# POSITIVE HEALTH, DIGNITY AND PREVENTION



## **OPERATIONAL GUIDELINES**





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### **ACKNOWLEDGEMENTS**

The Global Network of People Living with HIV (GNP+) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) jointly developed Positive Health, Dignity and Prevention: Operational Guidelines. We are grateful to our partners who participated in consultations and contributed to the development of the Positive Health, Dignity and Prevention concept (2009), the Policy Framework (2011) and now these Operational Guidelines (2013). It has been a long and informative journey, from the inception of the concept and shifting 'Positive Prevention' to a holistic and comprehensive set of actions that meet the needs of people living with HIV; to regional consultations that reviewed, expanded and adapted the concept to regional contexts; to the elaboration of a Policy Framework (2011), which provides guidance to policy and decision makers; and now to the expansion of a programmatic operational guideline.

These Operational Guidelines would not have been possible without the support of a dedicated and committed working group: Kevin O'Reilly (WHO Geneva), Nelson Otwoma (NEPHAK, Kenya), Georgina Caswell (GNP+), Svetlana Moroz (All-Ukrainian Network of PLHIV) and UNAIDS staff. GNP+ and UNAIDS are also indebted to the tireless contribution of Xavier Hospital (UNESCO Dakar) and the advice of Odilon Couzin on appropriate indicators and monitoring and evaluation in general. We are particularly grateful to the advisory group, who provided guidance on content development and on the follow-up actions that will ensure the Guidelines' use at the country level: Pam Bachanas (CDC, United States), Lynn Collins (UNFPA), Deloris Dockrey (GNP+ North America), Beri Hull (ICW), Anuar Lunar (RedLA+), Kevin Moody (GNP+), Ken Morrison (Futures Group), Nicolas Ritter (NAP+ Indian Ocean Region) and Violeta Ross (RedBol+). And, finally, we are grateful to all the partner organisations and individuals who reviewed the Guidelines and provided insightful comments on improvement and advice on implementation.

GNP+ and UNAIDS would also like to thank all their partners who have supported the process since 2009, and in particular all of the UNAIDS Co-sponsors, the International HIV/AIDS Alliance, the Bill and Melinda Gates Foundation, US Agency for International Development, United States CDC, Futures Group International, regional and national networks of people living with HIV, and countless civil society organisations and experts. Most importantly, GNP+ and UNAIDS are indebted to all those people living with HIV who have informed the development of Positive Health, Dignity and Prevention.

#### Published by:

The Global Network of People Living with HIV (www.gnpplus.net E-mail: infognp@gnpplus.net) UNAIDS (www.unaids.org)

UNAIDS / JC2514E (English original, June 2013)

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Joint United Nations Programme on HIV/AIDS (UNAIDS)

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WHO Library Cataloguing-in-Publication Data Positive Health, Dignity and Prevention: Operational Guidelines. "UNAIDS / JC2514E".

ISBN 978-92-9253-030-3

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#### Suggested citation:

UNAIDS, GNP+. 2013. Positive Health, Dignity and Prevention: Operational Guidelines. Geneva and Amsterdam

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### **ACRONYMS**

**AIDS** Acquired Immune Deficiency Syndrome

**ART** Antiretroviral Therapy

**ARV** Antiretroviral

**CBO** Community-based Organisation **CCM** Country Coordinating Mechanism

**CDC** (United States) Centres for Disease Control and Prevention

**CSS** Community Systems Strengthening

**GBV** Gender-based Violence

GIPA Greater Involvement of People Living with HIV GIOBAL Network of People Living with HIV

**HIV** Human Immunodeficiency Virus

**ICW** International Community of Women Living with HIV

**ILO** International Labour Organization

IPPF International Planned Parenthood Federation
 ITPC International Treatment Preparedness Coalition
 WERG UNAIDS Monitoring and Evaluation Reference Group

MSM Men who have Sex with Men
NCPI National Composite Policy Index
NGO Non-governmental Organisation
OST Opiate Substitution Therapy
OVC Orphans and Vulnerable Children

**PEP** Post-Exposure Prophylaxis

**PEPFAR** U.S. President's Emergency Plan for AIDS Relief

**PLHIV** People Living with HIV

**PMTCT** Prevention of Mother-to-Child Transmission of HIV,

also seen as Prevention of Vertical Transmission, PVT

**PREP** Pre-Exposure Prophylaxis

**SMART** Specific, Measurable, Attainable/Achievable, Relevant, and Time-bound

**SRHR** Sexual and Reproductive Health and Rights

**STI** Sexually Transmitted Infection

**TB** Tuberculosis

**TMAP** Treatment Monitoring and Advocacy Project

**UN** United Nation

UNAIDS Joint United Nations Programme on HIV/AIDS UNDP United Nations Development Programme

**UNESCO** United Nations Education, Science and Culture Organization

**UNFPA** United Nations Population Fund

**UNGASS** United Nations General Assembly Special Session on HIV/AIDS

VCT Voluntary Counselling and Testing
WHO World Health Organization

**WHO** World Health Organization **YPLHIV** Young People Living with HIV

### **FOREWORD**

Positive Health, Dignity and Prevention represents a fundamental shift in the way in which people living with HIV are involved in the HIV response:

- It calls for leadership by people living with HIV, including those from key populations.
- It transforms the concept of access to services, from a simple biomedical model to a holistic approach to meeting the needs of people living with HIV and their families in their communities.
- It puts the person living with HIV in the centre, and calls for a comprehensive set of actions at policy and service delivery levels that take into consideration the individual's lived environment.
- It recognises the importance of meeting not only the person's clinical needs but also their health needs and to protect their human rights.

Positive Health, Dignity and Prevention was developed for and by people living with HIV based on numerous consultations at the global, regional and national levels. It articulates the next stage in the HIV response, where people living with HIV are at the centre and services offered in an environment that is supportive to meet all the needs of people living with HIV and their families. Instead of being regarded by "positive prevention" programmes as mere recipients of care and vessels of a virus that needs to be contained, people living with HIV embrace a new paradigm where they are actively involved as part of the solution to the epidemic and not seen as part of the problem.

These guidelines articulate actions that can be taken at country level to reach the 2011 United Nations Political Declaration on HIV and AIDS: 15 million people on treatment, reduce sexual and drug-use related transmission of HIV by 50%, and stop new infections among children by 2015.

#### Zero new HIV infections

- Support programmes, policies and laws that create shared responsibility among everyone in their role to prevent new HIV infections irrespective of HIV status
- Remove policies and service practices that hinder access to means of prevention for people living with HIV, including the prevention of vertical transmission
- Scale-up access to antiretroviral (ARV) treatment for all people living with HIV, including key populations living with HIV who often face the greatest barriers to services, utilising the preventive benefits of treatment without compromising their human rights

#### Zero discrimination

- Support policies and programmes to change judgmental attitudes and eliminate discrimination in settings including, amongst others, health care services, the workplace, schools, communities, places of worship, and social protection services
- Support mechanisms that protect the rights of people living with HIV
- Empower people living with HIV to know their rights and engage meaningfully in all aspects of the response to HIV

#### Zero AIDS-related deaths

- Increase access to quality and life-long ARV treatment for all
- Meet the health needs of people living with HIV, beyond HIV treatment e.g. Hepatitis C and tuberculosis co-infections, non-communicable illnesses, sexual and reproductive health and rights and psycho-social support
- Link the HIV-response with social protection to help ensure that people living with HIV continue to be healthy and productive members of their communities

In an era marked by financial crises and limited resources for HIV, this approach provides hope. Combined with the 'Strategic Investment' approach it offers new opportunities to implement Positive Health, Dignity and Prevention through smarter and more strategic investments in HIV-programming that put the person living with HIV in the centre of a holistic response.

Kevin Moody, International Coordinator and CEO GNP+ Michel Sibidé, Executive Director UNAIDS

### **EXECUTIVE SUMMARY**

The primary goals of Positive Health, Dignity and Prevention are to improve the dignity, quality, and length of life of people living with HIV. If achieved, this will, in turn, have beneficial effects on their partners, families, and communities, including reducing the likelihood of new infections.

Positive Health, Dignity and Prevention is not just a new name for the concept of HIV prevention for and by people living with HIV, formerly known as 'positive prevention'. Rather, Positive Health, Dignity and Prevention is built upon a broader foundation that includes improving and maintaining the dignity of the individual living with HIV; supports and enhances the individual's physical, mental, emotional and sexual health; and, which, in turn, among other benefits, creates an enabling environment that will reduce the likelihood of new HIV infections.

Positive Health, Dignity and Prevention encompasses the full range of health and social justice issues for people living with HIV, and espouses the fundamental principles that responsibility for HIV prevention should be shared and that policies and programmes for people living with HIV should be designed and implemented with the meaningful involvement of people living with HIV.

By linking the social, health, and prevention needs of the person living with HIV within a human rights framework, Positive Health, Dignity and Prevention results in a more efficient use of resources, with outcomes that are more responsive to the needs of people living with HIV and more beneficial for their partners, families, and communities.

#### **OPERATIONAL GUIDELINES**

These guidelines describe the suggested steps for operationalising the Positive Health, Dignity and Prevention Policy Framework (2011) at the national level. As such, they are intended for national level use and, in particular, were designed for:

- Networks of people living with HIV;
- Non-governmental organisations (NGOs) and community-based organisations (CBOs) of people living with HIV;
- National governmental bodies;
- National coordination mechanisms;
- Civil society organisations<sup>[1]</sup>; and,
- Donors and development agencies.

Taken together, the Operational Guidelines in the pages that follow and the Policy Framework<sup>[2]</sup> represent a two-part package. They should be seen as living documents that adapt to the evolving needs of people living with HIV, the policies and programmes that serve them, and the lessons learned from country-level implementation.

#### PROGRAMMATIC COMPONENTS OF POSITIVE HEALTH, DIGNITY AND PREVENTION

Operationalising Positive Health, Dignity and Prevention does not involve creating new programmes, except in places where basic programmes do not currently exist. Rather, operationalisation focuses on creating linkages between existing programmes and improving the efficiency and responsiveness of programmes in meeting the needs of people living with HIV. Individual programmatic elements will inevitably differ from setting to setting according to local contexts.

<sup>1</sup> UNAIDS. 2011. UNAIDS guidance for partnerships with civil society, including people living with HIV and key populations; http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2012/JC2236\_guidance\_partnership\_civilsociety\_en.pdf

<sup>2</sup> GNP+, UNAIDS. 2011. Positive Health, Dignity and Prevention: A Policy Framework.

Programmatic components of Positive Health, Dignity and Prevention fall under the following eight (8) thematic areas:

- 1 EMPOWERMENT OF PEOPLE LIVING WITH HIV (PLHIV) AND NETWORKS OF PLHIV[3];
- 2 HEALTH PROMOTION AND ACCESS:
- 3 GENDER EQUALITY;
- 4 HUMAN RIGHTS:
- 5 PREVENTION OF NEW INFECTIONS;
- 6 SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS:
- 7 SOCIAL AND ECONOMIC SUPPORT; AND
- 8 MEASURING IMPACT.

The meaningful involvement and engagement of individuals and networks of people living with HIV throughout all levels and stages of the design, implementation, monitoring and evaluation of activities is a common thread running through all eight components.

#### THESE OPERATIONAL GUIDELINES CONSIST OF THREE MAIN STEPS:

For each step, suggested actions are offered to guide national stakeholders on evaluating current situations and on planning and implementing actions that meet the goals of Positive Health, Dignity and Prevention.



### Assessing the national context and preparatory steps for operationalising Positive Health, Dignity and Prevention

The initial step in operationalising Positive Health, Dignity and Prevention at the country level is understanding the national context. Positive Health, Dignity and Prevention involves putting in place a comprehensive 'package' of programmes that situates PLHIV at the centre of the response, taking into consideration not only what services and programmes are available to them, but also the political, legal, socio-economic and cultural environment in which the individual lives specific to the community and country. Not all organisations and stakeholders involved in the national response to HIV will be able to deliver on all proposed actions. Assessing, analysing and understanding the national environment (e.g., legal, policy, political, social, cultural, etc.), as well as the human and financial resources available to carry out such programmes and determining the organisational capacity and role relative to priorities vis-à-vis Positive Health, Dignity and Prevention and PLHIV, are critical first steps.

In other words, 'knowing your epidemic' within the context of Positive Health, Dignity and Prevention extends beyond simply knowing the main modes of HIV transmission and the relative prevalence among sub-populations. Knowing your epidemic within the context of Positive Health, Dignity and Prevention requires both understanding the epidemiology in the country and understanding the political, legal, socio-cultural and economic background within which the HIV epidemic and the national response is situated. It also requires understanding the initiatives and/or programmes that need to be put in place to address HIV-related vulnerabilities.



#### Operationalising each component of Positive Health, Dignity and Prevention

For each component of Positive Health, Dignity and Prevention, guidance is provided in terms of:

- Background information and the rationale for adopting the Positive Health, Dignity and Prevention framework;
- Considerations for giving particular attention to key populations living with HIV;
- A detailed set of concrete and specific activities for each component and sub-component; and,
- A suggested sequential series of activities that can support national stakeholders to assess where they are and
  how to move from the current situation to outcomes and strategies that are in line with Positive Health, Dignity and
  Prevention principles and values.

<sup>3</sup> We have chosen to use the phrase networks of people living with HIV, which may include networks, associations or other organised groups of HIV-positive individuals at the local, national, regional or international levels. In addition, we recognise that individual countries may have several bodies of people living with HIV which may or may not work as a network. Thus, for convenience, we use 'networks of PLHIV' to refer to such groups throughout the text, whilst recognising that the term encompasses more than a traditional definition of 'network'.

In particular, components are further broken down into thematic sub-sections, and are described in detail in the corresponding sections. These sub-sections include:

### EMPOWERMENT OF PLHIV AND NETWORKS OF PLHIV

- Meaningful involvement of networks of PLHIV
- Meaningful involvement of PLHIV
- Capacity building of networks of PLHIV
- PLHIV leadership development
- PLHIV legal, rights and health literacy

#### **HEALTH PROMOTION AND ACCESS**

- Treatment access for PLHIV
- Care and support for PLHIV
- Prevention, diagnosis and treatment of other infections and illnesses for PLHIV
- Quality assurance and improvement of health services for PLHIV

#### **GENDER EQUALITY**

- Centralised and systemic responses
- Service provision to all
- Empowerment of communities and individuals
- Social drivers and the general population

#### **HUMAN RIGHTS**

- Legal and policy reform and enforcement
- Social change and empowerment
- Monitoring and responding to human rights violations

#### PREVENTION OF NEW INFECTIONS

- Comprehensive education that fosters shared responsibility
- Access to prevention technologies
- Access to prevention of vertical transmission services
- Antiretroviral therapy (ART) and treatment for prevention
- Support for sero-different couples

### SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS

- Sexual health and wellbeing
- Reproductive health
- Sex and sexuality
- Sexual and reproductive health and human rights

#### SOCIAL AND ECONOMIC SUPPORT

- Employment and economic empowerment
- Social protection
- Support for caregivers
- Healthy living conditions

#### **MEASURING IMPACT**

- · Developing good policy and practice
- Generating and applying evidence
- Development and adaptation of indicators
- Resources for M&E



### Planning and management of a Positive Health, Dignity and Prevention programme of actions

The Guidelines offer examples of how to operationalise the components as a single comprehensive and coherent programme of action through nine action areas. This includes planning and managing a comprehensive country-level programme and would entail the following:

#### ADVOCACY AND POLICY DIALOGUE

- Advocate for Positive Health, Dignity and Prevention
- Mobilise political will and leadership

#### **PLANNING**

 Develop long-term (3 to 5 years) and annual work plans for each of the components as well as programme-wide actions, with costed and SMART<sup>[4]</sup> activities, inputs, outputs, outcomes, objectives and goals. Mobilise additional resources if needed.

#### **IMPLEMENTATION**

 Implement long-term and annual work plans in partnership with networks of PLHIV, civil society, and all relevant and appropriate stakeholders

#### **INTEGRATION / ALIGNMENT**

 Integrate the framework for action for Positive Health, Dignity and Prevention into the broader work related to the national response to HIV and sexual and reproductive health and rights (SRHR)

<sup>4</sup> SMART refers to a formulation which is specific, measurable, attainable or achievable, relevant and time-bound.

#### COORDINATION

- Ensure coordination, constructive dialogue and information-sharing between diverse groups of partners
- Foster partnerships through inclusive, wellresourced coordination mechanisms

#### CONTINUOUS EVIDENCE GATHERING

• Gather evidence on a continuous basis at all phases of implementation – that is, during development, implementation, adaptation and improvement – with the meaningful involvement and leadership of PLHIV

#### MONITORING AND EVALUATION

- Develop new and/or use existing sets of appropriate indicators
- Ensure that monitoring and evaluation is an ongoing aspect of every action
- Dedicate adequate resources (human, technical and financial) in the operationalisation of a monitoring and evaluation (M&E) framework and mechanism

#### ADAPTATION AND IMPROVEMENT

- Adapt and improve activities in long-term and annual work plans on a regular basis based on lessons learned and in order to incorporate emerging evidence and guidelines
- Document and share the lessons learned with partners at national, regional and global levels

#### SUPPORTING RESOURCES AND CHECKLISTS

Following the detailed description of each of the steps included in these Guidelines, a number of annexes provide supplemental material that may be useful for each component of Positive Health, Dignity and Prevention. Annex 1 expands on Steps 1 and 2 by providing a more detailed suggested process of assessing, developing and implementing programmatic components.

While this document attempts to provide guidelines that are common to all stakeholders, Annexes 2-6 provide suggested additional areas of work which are stakeholder-specific.

Lastly, Annex 7 provides a list of indicators that can be used at all stages to support monitoring and evaluation efforts.

#### SUGGESTION ON HOW TO READ THE DOCUMENT

These guidelines are meant to be read and used in their totality. However, we suggest that after the first reading, the reader may return to different sections (e.g., Step 1, or Step 2: Human Rights) or use different supportive tables and checklists, depending on the immediate programme priorities, local context and phase of discussions with partners.

Each step has descriptive text on issues that are found in more than one section – i.e., the inter-linkage of components that is assumed by Positive Health, Dignity and Prevention. The repetitions are intentional. Furthermore, it is hoped that practical lessons learned from piloting and use of the Guidelines at country level will allow UNAIDS and GNP+ to review and revise the structure and content of this document.

### INTRODUCTION

Positive Health, Dignity and Prevention is not just a new name for the concept of HIV prevention for and by people living with HIV, formerly known as 'positive prevention'. Rather, Positive Health, Dignity and Prevention is built upon a broader understanding that includes improving and maintaining the dignity of the individual living with HIV; supporting and enhancing that individual's physical, mental, emotional and sexual health; and, in turn, among other benefits, creating an enabling environment that will reduce the likelihood of new HIV infections.

Positive Health, Dignity and Prevention encompasses the full range of health and social justice issues for people living with HIV. It espouses the fundamental principles that responsibility for HIV prevention should be shared, and that policies and programmes for people living with HIV should be designed and implemented with the meaningful involvement of people living with HIV.

By linking together the social, health, and prevention needs of the individual living with HIV within a human-rights framework, Positive Health, Dignity and Prevention results in a more efficient use of resources, generating outcomes that are more responsive to the needs of people living with HIV and more beneficial for their partners, families, and communities.

These Guidelines are the first step towards operationalising Positive Health, Dignity and Prevention. It should be seen as a living document that is adaptable to the evolving needs of people living with HIV and the policies and programmes that serve them.

### BACKGROUND ON DEVELOPING POSITIVE HEALTH, DIGNITY AND PREVENTION

The development of Positive Health, Dignity and Prevention has relied upon a series of consultations that have taken place at various stages throughout the process.

Initial consultations with PLHIV on HIV prevention occurred in Monaco in January 2008 as a prelude to a summit

entitled LIVING 2008, which took place prior to the XVII International AIDS Conference in Mexico in July–August 2008. The sessions on 'Positive Prevention' at LIVING 2008 generated considerable debate and controversy. Subsequently, GNP+ and UNAIDS co-organised an International Technical Consultation in Tunisia in April 2009, where participants agreed on a new concept—Positive Health, Dignity and Prevention<sup>[5]</sup>.

Following this, a series of consultations<sup>[6]</sup> were led by regional networks of PLHIV and UNAIDS regional offices, involving regional and national networks of PLHIV, civil society organisations, development agencies and donors. These consultations resulted in enhanced understanding of regional specificities and how the Guidelines might be adapted with specific sets of actions on how to move the agenda forward within each region. Moreover, these consultations highlighted the need to develop operational guidelines capable of supporting national stakeholders in moving from policy to action for Positive Health, Dignity and Prevention.

Finally, in early 2010, GNP+ undertook consultations and operational research with the Population Council and national networks of people living with HIV in Bolivia (Redbol+), Tanzania (NACOPHA), and Viet Nam (VNP+). This work resulted in a methodology adaptable to a particular country context with the leadership of national networks of PLHIV. The methodology includes steps for gathering evidence and developing partnership-driven, evidence-informed national actions.

In parallel, GNP+ and UNAIDS, with support from their partners and informed by the outcomes of regional consultations and national action research, developed the Positive Health, Dignity and Prevention: Policy Framework (January 2011)<sup>[7]</sup>.

- 5 GNP+, UNAIDS. 2009. Technical Consultation Report: Positive Health, Dignity and Prevention. Tunis, April 2009.
- 6 Regional consultations included Asia and Pacific (June 2009 and August 2009), Africa Francophone community (Casablanca, March 2010), Caribbean (June 2011), and West and Central Africa (September 2011).
- 7 GNP+, UNAIDS. 2011. Positive Health, Dignity and Prevention: A Policy Framework.

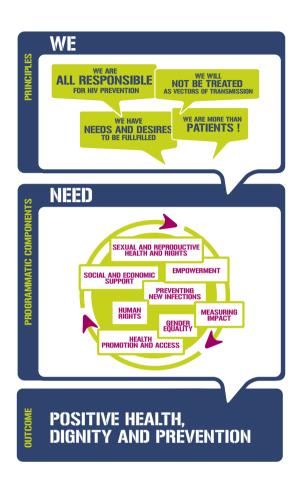
#### WHY THESE OPERATIONAL GUIDELINES

These Operational Guidelines complement the Policy Framework and other Positive Health, Dignity and Prevention related guidance packages (e.g., Tanzania Positive Health, Dignity and Prevention Operational Guidance). Consultations at the regional and national levels have shown that the Policy Framework requires additional guidance in terms of how to convert the 'policy formulations' into concrete and coherent sets of activities to be carried out by diverse stakeholders at the country level. The Operational Guidelines here offer guidance and support regarding the rationale for the development of the Positive Health, Dignity and Prevention Policy Framework and the suggested steps and actions necessary for moving from policy to activities (i.e., this document).

### SCOPE AND LIMITATIONS OF THESE OPERATIONAL GUIDELINES

The Positive Health, Dignity and Prevention Operational Guidelines are intended as a roadmap for the development and implementation of policy, strategy and programmatic actions at the national level. Designed for stakeholders at the national level, they have been written with the following specifically in mind:

- Networks of people living with HIV;
- National governmental bodies;
- National coordination mechanisms;
- Civil society organisations; and
- Donors and development agencies





This version of the Operational Guidelines has not yet been extensively field tested. Future work will focus on the adaptation and improvement of these guidelines based on practical lessons learned from pilot testing and use at country level. The national-level application of the Guidelines is currently in the planning stage. Future work will also address how to adapt and contextualise the Operational Guidelines to country-specific situations. It is expected that piloting will result in revisions with respect to content, structure, and further elaboration of Step 3, which concerns implementation at country level, including costing and financing, development of new/more appropriate indicators, embedding work into National Strategic Plans, etc

### PRINCIPLES, VALUES, GOALS AND OBJECTIVES

OF POSITIVE HEALTH DIGNITY AND PREVENTION

#### **PRINCIPLES**

The following represents the shared understanding of Positive Health, Dignity and Prevention and the principles that inform it, as defined by people living with HIV.

WE ARE MORE THAN **PATIENTS** 

People living with HIV are leaders in the design, programming, implementation, research, monitoring and evaluation of all programmes and policies affecting them. People living with HIV have substantial knowledge, experience and insight into the issues that are important for them and regarding strategies for responding effectively to the epidemic. If the health, dignity and prevention needs of people living with HIV are to be adequately addressed, PLHIV must be meaningfully involved in all aspects of policies and programmes that affect them.

WE WILL
NOT BE TREATED
AS VECTORS OF TRANSMISSION

A human rights—based approach is the foundation of Positive Health, Dignity and Prevention<sup>[8]</sup>. People living with HIV strive for policies and programmes that do not oppress, manage, control, abuse or criminalise them. Positive Health, Dignity and Prevention requires a human rights framework<sup>[9]</sup> (including rights-based approaches to HIV programming) supported by protective laws to: ensure non-discrimination; reduce stigma; provide access to justice; and change harmful gender norms. Such policies and programmes must enable people living with HIV to protect themselves and others—not through fear but through empowerment, and with dignity.

ALL RESPONSIBLE FOR HIV PREVENTION

Preventing new HIV infections is the shared responsibility of everyone irrespective of HIV status. As such, Positive Health, Dignity and Prevention includes people living with HIV in all aspects of HIV prevention. It rejects the notion that people living with HIV are solely responsible for the health of those with whom they interact. It also acknowledges and addresses HIV-related stigma and other social determinants of health that influence the vulnerability of those affected. Furthermore, Positive Health, Dignity and Prevention promotes supportive policies and programmes that help empower individuals irrespective of their HIV status to take responsibility for their own health and well being. By doing so, this will have a positive impact on partners, families and communities.

WE HAVE
NEEDS AND DESIRES
TO BE FULLFILLED

Sexual and reproductive health and rights<sup>[10]</sup> must be recognised and exercised by everyone regardless of his or her HIV status. Following diagnosis, people living with HIV continue to have the same needs and desires for intimacy, sexual activity, family, and community as before. Positive Health, Dignity and Prevention aims to create the conditions for people living with HIV and their sexual partners to be free to make informed choices regarding whether and how to be sexually active and fulfilled and whether, when and how to conceive and enjoy a family.

<sup>8</sup> See also, Strategic Direction 3: Advance human rights and gender equality for the HIV response, UNAIDS. Getting to Zero: 2011-15 Strategy, 2010.

<sup>9</sup> For a commonly agreed upon definition of human rights-based approach, we generally refer to that which was adopted in 2003 See http://www.unfpa.org/rights/approaches.htm for a thorough discussion and description.

<sup>10</sup> Sexual rights are a component of human rights. Sexual rights are constituted by a set of entitlements related to sexuality that emanate from the rights to freedom, equality, privacy, autonomy, integrity and dignity of all people. See: IPPF. Sexual Rights: an IPPF declaration, 2008.

#### **VALUES**

Positive Health, Dignity and Prevention can only be achieved through the following values:

- A supportive and protective legal and policy environment that aims for a world free of HIV-related stigma and discrimination.
- A focus on improving and maintaining the health and well-being of people living with HIV, which, in turn, contributes to the health and well-being of their partners, families and communities.<sup>[11]</sup>
- The promotion of holistic health and wellness, including universal and equitable access to voluntary HIV counselling; confidential testing, care and support; and timely access to voluntary treatment and monitoring.
- The ready availability of means to address factors that undermine health and dignity, including poverty and food insecurity; lack of mental and psychosocial support; lack of educational opportunity; social exclusion; gender inequality; and stigma and discrimination based on HIV-positive status; as well as behaviours such as injecting drug use, sex work and/or sex between men, and identities such as being lesbian, gay, bisexual, transgender or intersex.
- Responding to the needs of key populations<sup>[12]</sup>, including the particular and specific needs of young people and women, and through respectful programmes tailored to specific contexts and the diversity of people living with HIV.

#### **GOALS AND OBJECTIVES**

The primary goals of Positive Health, Dignity and Prevention are to improve the dignity, quality and length of life of people living with HIV. This, in turn, will benefit partners, families, and communities, including reducing the likelihood of new infections.

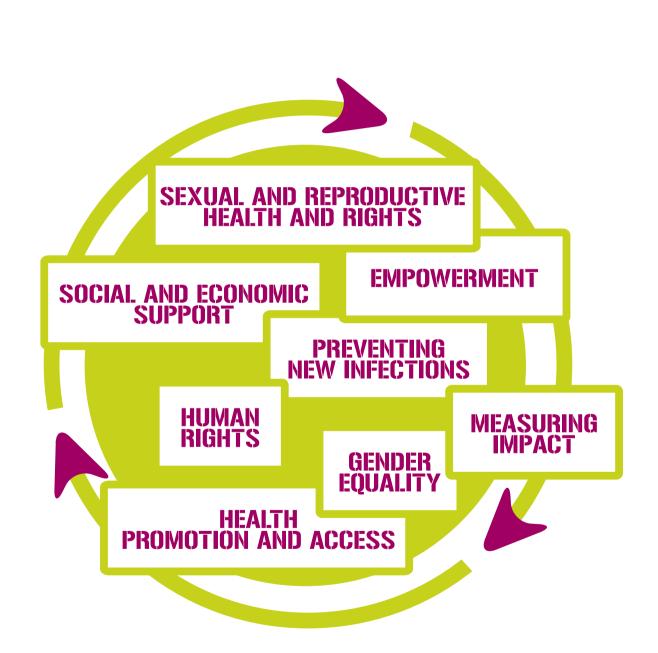
Specifically, Positive Health, Dignity and Prevention requires promoting and affirming the empowerment of people living with HIV through the following objectives:

- Increasing access to and the understanding of evidence-informed, human rights based policies and programmes that support individuals living with HIV to make choices that address their needs and allow them to live healthy lives free from stigma and discrimination.
- Scaling up and supporting existing HIV counselling and testing, care, support, treatment, and prevention programmes that are community-owned and -led, and increasing access to high-quality, rights-based health services, including sexual and reproductive health.
- Scaling up and supporting literacy programmes in health, treatment, prevention, human rights, and the law, and ensuring that human rights are promoted and implemented through relevant programmes and protections.
- Ensuring that undiagnosed and diagnosed people living with HIV, along with their partners and communities, are included in HIV prevention programmes that highlight shared responsibility regardless of known or perceived HIV status, and that all PLHIV have opportunities for, rather than experience barriers to, empowering themselves and their sexual partner(s).
- Scaling up and supporting social capital programmes that focus on community-driven, sustainable responses to HIV by investing in community development, networking, capacity building, and resources for organisations and networks of people living with HIV.

Operationalising Positive Health, Dignity and Prevention does not necessarily entail the creation of new programmes, except where basic programmes currently do not exist. Rather, operatonalisation focuses on using Positive Health, Dignity and Prevention to create linkages among existing programmes, as well as taking them to scale, so that they are more efficient and more responsive to the needs of people living with HIV.

<sup>11</sup> Within the context of new evidence on treatment for prevention, access to treatment for all people living with HIV has implications in protecting human capital of all, irrespective of HIV status.

<sup>12</sup> Key populations at higher risk of living with HIV due to their social or legal status and/or behaviour include 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.



## ASSESSING WHERE YOU ARE:

### NATIONAL POLICY, LEGAL AND PROGRAMME ENVIRONMENT

Positive Health, Dignity and Prevention involves implementation of a comprehensive 'package' of programmes that situate PLHIV at the centre of the response, taking into consideration not only available services and programmes, but also the political, legal, socio-economic and cultural environment in which the individual lives in his or her own community and country. Not all organisations and stakeholders involved in the national response to HIV will be able to deliver on all proposed actions. Assessing, analysing and understanding the national environment (e.g., legal, policy, political, social, cultural, etc.) and determining respective organisational capacities and roles relative to Positive Health, Dignity and Prevention and PLHIV priorities are critical first steps. Many existing assessments can be used for this purpose<sup>[13]</sup>.

In other words, 'knowing your epidemic' within the context of Positive Health, Dignity and Prevention extends beyond simply knowing the main modes of HIV transmission and relative HIV prevalence by sub-populations. Knowing your epidemic within the context of Positive Health, Dignity and Prevention requires understanding both national epidemiology and the political, legal, socio-cultural, and economic context within which the HIV epidemic and the national response are situated and the initiatives and programmes necessary to reduce vulnerability to the impact of HIV. It also requires understanding pertinent issues relating to the financing of country-level responses. This is particularly important in light of recent funding challenges experienced by agencies such the Global Fund to Fight AIDS, Tuberculosis and Malaria as well as PEPFAR and others, and funding consequences for many national responses financed through these agencies.

### ASSESSING WHERE YOU ARE: NATIONAL POLICY, LEGAL AND PROGRAMME ENVIRONMENT

### SUGGESTED STEPS:

- 1. Who are the people living with HIV in your country?
- 2. Beyond age and sex gender, wealth quintile, rural/urban, ethnicity, disability, etc. And what are the incidence rates in addition to prevalence?
- 3. What evidence is available on the experiences and priority needs of PLHIV in your country?
- 4. Beyond access to treatment experienced stigma and discrimination, human rights, social protection and services, quality of life, reproductive health, education, treatment adherence, non-communicable diseases, etc.
- 5. How is the response to HIV in your country coordinated?
- 6. Structures, composition, membership requirements
- 7. What are the main legal and policy frameworks that define how and where the response to HIV in your country is directed and delivered?
- 8. National strategic plans, Global Fund proposals and frameworks, laws that relate to PLHIV, protective laws, criminalising laws, PLHIV and key populations policies and laws, etc.
- 9. What are the social, economic and legal determinants of vulnerability to HIV?
- 10. What resources are available to respond effectively to and meet the needs of PLHIV?
- 11. Who are the main stakeholders responding to HIV in your country?
- 12. What are the roles of civil society and key populations in the response to HIV?
- 13. What is the role of networks of PLHIV in the response to HIV?
- 14. What is your organisation's role in the HIV response within the framework of Positive Health, Dignity and Prevention?

Please refer to Annex 1 for a more detailed suggested steps that can be followed

STEP

<sup>13</sup> For example, see Rapid Assessment Tool for Sexual and Reproductive Health and HIV Linkages, PLHIV Stigma Index, UN Women and UNAIDS Gender Assessment Tool etc. (See also Section 6: Useful Resources and References).



### **ASSESS AND OPERATIONALISE** THE COMPONENTS OF POSITIVE HEALTH, DIGNITY AND PREVENTION

The sections below will guide you as you consider how your organisation or country currently responds to the eight (8) components of Positive Health, Dignity and Prevention. Each section provides suggestions regarding how to operationalise each component. Although not all components will be relevant to all organisations or national stakeholders, because of the inter-connected nature between components, we recommend that you review all sub-sections. Individual programmatic elements and actions will differ from setting to setting given that local needs, resources and experiences vary.

#### EMPOWERMENT OF PLHIV AND NETWORKS OF PLHIV

Empowerment is one of the most significant components of Positive Health, Dignity and Prevention and is an underlying sub-component of all programmes and services outlined throughout this document. Positive Health, Dignity and Prevention is not a 'new' programme, but rather a shift towards a 'comprehensive package' that synergistically combines programmes using the 'lens' of a people- and rights-centred approach. In this way, the impact is greater than the sum of the individual elements. Empowerment needs to happen at the individual level and at the community level.

The ethos of Positive Health, Dignity and Prevention is the empowerment of people living with HIV to be the drivers of change (individually and as an organised community), to be enabled to make healthy and educated decisions about their health and support the health of their loved ones, to be active and constructive contributors to national responses to HIV, and to enable social, cultural and economic change in their communities.

As used here, the term 'empowerment' is an expanded and more inclusive approach to achieving the Greater Involvement of People living with HIV/AIDS (GIPA) principle, which has underpinned the response to HIV since the beginning of global efforts to respond to the epidemic<sup>[14]</sup>. Empowerment within the context of Positive Health, Dignity and Prevention requires the meaningful involvement of people living with HIV – individually and as networks and organisations - and enabling people living with HIV to become leaders of change and the decision makers for

positive health outcomes for themselves, their loved ones and their communities

To achieve the outcomes above, and to ensure that empowerment for Positive Health, Dignity and Prevention is addressed appropriately, concerted efforts and resources must be dedicated to support PLHIV and networks of PLHIV to be equal partners. The meaningful participation of national networks of PLHIV in country-level AIDS councils and country coordinating mechanisms, for example, requires support to the network so that it may remain a strong, sustainable, accountable, representative and skilled organisation.

Self-empowerment of PLHIV to become 'health literate' requires resources and programmes that reach PLHIV and do so through rights-based and people-centred approaches - allowing 'information' to be inculcated into 'knowledge' and positive change.

This section describes the expected elements and actions under each facet of empowerment, and offers an example of the steps that may be taken to improve the level and quality of empowerment of PLHIV and networks of PLHIV. Specific national contexts may require different steps, and thus it is not expected that every organisation or country will follow the same path. However, to achieve the goal of empowerment, the Positive Health, Dignity and Prevention articulates the need to ensure that all of its elements are met regardless of the exact steps a country defines on its own path towards realisation.

<sup>14</sup> For a complete description and historical background to the GIPA Principle, see "Greater involvement of people living with HIV: Good Practice Guide", pages 8 to 14. International HIV/AIDS Alliance and GNP+, 2010

#### **KEY POPULATIONS LIVING WITH HIV**

Throughout all actions to improve the empowerment of PLHIV, the particular need to ensure empowerment of key populations living with HIV is crucial in determining success and reaching the goals and outcomes of empowerment. Women and girls, children and young people living with HIV, men who have sex with men (MSM), sex workers, prisoners, and people who use drugs living with HIV all carry a burden of disease that is disproportionate. Moreover, they face gender inequalities, stigmatising and discriminatory attitudes, legal barriers, and other vulnerabilities that may not allow them to participate as decision makers, visible leaders and advocates in their communities and networks. In some contexts migrants, refugees, asylum seekers, internally displaced persons (IDPs), and stateless people living with HIV may also be relevant key populations. Thus, the action areas for empowerment must ensure that networks of PLHIV, for example, are supported to overcome issues of sexism, stigmatising attitudes towards sex workers and people who use drugs, and homophobia. They must also be supported to overcome legal barriers to ensure that networks' responses are developed by and with key populations living with HIV. Leadership programmes for PLHIV must also be inclusive and allow people most vulnerable to gain equal access to leadership development opportunities. Treatment, legal and health literacy must be responsive to key populations and enable MSM, sex workers, prisoners, and people who use drugs living with HIV to access health, treatment, and legal support that is appropriate for them and that does not heighten their vulnerability.

#### EMPOWERMENT OF PLHIV AND NETWORKS OF PLHIV

#### GOAL

Empowerment will lead to the improved effectiveness and appropriateness of services, programmes, policies and strategies through the meaningful participation of PLHIV at all stages of design, implementation, monitoring and evaluation.

#### SUB-COMPONENTS

- Meaningful involvement of networks of PLHIV
- · Meaningful involvement of PLHIV
- · Capacity building of networks of PLHIV
- PLHIV leadership development
- PLHIV legal, rights and health literacy

#### EXPECTED OUTCOMES

- · Evidence-informed policies, strategies, and services for PLHIV through the meaningful, coordinated and collective participation of PLHIV
- Improved participation of networks of PLHIV in coordinating bodies in the response to HIV (national, provincial and local community)
- Improved participation of PLHIV in the response to HIV at all levels through self-empowerment, leadership and literacy programmes, and social mobilisation
- Strengthened accountability and sustainability of networks of PLHIV through strengthened capacity in management and leadership development
- · Improved access to rights and services and improved health outcomes for PLHIV through legal, health and treatment literacy programmes

#### MEANINGFUL INVOLVEMENT OF NETWORKS OF PLHIV

#### FOR:

- National and community-based AIDS councils, programmes and committees, including parliamentary bodies
- Country Coordinating Mechanisms (CCMs)
- Sector-wide national coordinating bodies (e.g., Ministries of Health, Education, Labour, Justice and Social Protection Coordination)
- Local government coordination, local community level and grassroots committees
- Limited- or short-term committees and commissions formed to develop, evaluate, or monitor specific work (e.g., human rights tribunals, external evaluation committees of national or district-level programmes, evaluation of legal barriers to access treatment and prevention, etc.)
- All stages of development, design, implementation, monitoring, evaluation and participation
  of programmes (e.g., adaptation of testing and counselling programmes to meet new
  guidelines, implementation of treatment services, etc.)

### TO ACHIEVE OUTCOMES:

- → National policies and programmes are informed by the actual experiences and meet the needs of people living with HIV at the local level
- → Networks of people living with HIV contribute to the implementation, monitoring and evaluation of programmes
- → National policies and programmes aimed at people living with HIV are rendered effective and efficient by ensuring relevance, appropriateness, prioritisation, accessibility and acceptance to the end user that is, the person living with HIV
- → Networks of people living with HIV can better serve their constituents through effective partnerships, knowledge sharing, and improved relevance of work to national priorities

### SUGGESTED STEPS:

- 1. Map processes and mechanisms that provide opportunities for engagement
- 2. Assess the current format of engagement
- 3. Map existing guidelines and documentation
- 4. Identify and assess successes and challenges
- 5. Look for evidence related to the level as well as quality of involvement
- 6. Take follow-up steps to improve the level and quality of engagement of networks of PLHIV
  - Advocate
  - Mobilise political and organisational support
  - Involve the network of PLHIV
  - Review membership of partners and barriers to the engagement of civil society, including fair systems for selection based on representation
  - Adapt current policies and remove legal barriers
  - Adapt current guidelines and terms of reference of coordination
  - Address stigmatising attitudes
  - Determine resources required
  - Monitor progress

Please refer to Annex 1 for a more detailed suggested steps that can be followed

MEANINGFUL INVOLVEMENT OF PLHIV		
FOR:	<ul> <li>Accessing services and programmes</li> <li>Delivering services and programmes</li> <li>Designing, planning and managing services and programmes</li> <li>Developing and shaping policy and legal frameworks</li> <li>Management of organisations</li> <li>Governance and coordination</li> <li>Social mobilisation and capital (citizenship) as an entry point</li> </ul>	
TO ACHIEVE OUTCOMES :	<ul> <li>→ Improved responsiveness of policies and programmes aimed at people living with HIV by ensuring that they are relevant and appropriate to the end user – that is, people living with HIV</li> <li>→ Increased access to treatment, prevention, care and support services by people living with HIV</li> <li>→ Improved quality of services and programmes</li> <li>→ Strengthened coordination of planning, monitoring and evaluation of local and national responses</li> </ul>	
SUGGESTED STEPS:	<ol> <li>Map services, programmes and processes that provide opportunities of engagement</li> <li>Assess the current format of engagement</li> <li>Map existing guidelines and documentation and evidence on the engagement of PLHIV thus far</li> <li>Assess the success and challenge factors</li> <li>Take follow-up steps to improve the level and quality of involvement of PLHIV         <ul> <li>Advocate</li> <li>Reach out to the local network of people living with HIV</li> <li>Determine priority areas and programmes</li> <li>Mobilise political and organisational leadership</li> <li>Adapt current policies and guidelines</li> <li>Address stigmatising attitudes</li> <li>Review organisational management</li> <li>Determine resources</li> <li>Monitor engagement and share good policy and practice</li> </ul> </li> </ol>	
	Please refer to Annex 1 for a more detailed suggested steps that can be followed	

PLHIV LEADERSHIP DEVELOPMENT		
FOR:	<ul> <li>Leadership development, accountability and renewal</li> <li>Programme development and management</li> <li>Advocacy, public speaking, communications and lobbying</li> <li>Participation of key populations, young people and women living with HIV in leadership</li> <li>Capacity and skills building on thematic issues</li> <li>Planning actions for political change and responding to emerging and emergency priorities</li> </ul>	
TO ACHIEVE OUTCOMES :	<ul> <li>→ Improved effectiveness and representativeness of networks of people living with HIV through accountable leadership</li> <li>→ Strengthened participation of people living with HIV in national processes and services</li> <li>→ Greater participation of key populations, women and young people living with HIV in networks of people living with HIV as well as national processes and mechanisms</li> <li>→ Improved knowledge-sharing among and from people living with HIV</li> </ul>	
SUGGESTED STEPS:	<ol> <li>Map services, programmes and processes that provide opportunities for leadership development and renewal of PLHIV</li> <li>Map other services, programmes and services for leadership development and renewal</li> <li>Map opportunities for capacity strengthening in technical thematic areas</li> <li>Assess lessons learned, opportunities, successes and challenges</li> <li>Take follow-up steps to improve the leadership development and renewal of PLHIV         <ul> <li>Advocate</li> <li>Reach out to current leadership among PLHIV</li> <li>Reach out to the local network of people living with HIV</li> <li>Mobilise organisational support and create opportunities</li> <li>Review organisational management</li> <li>Determine the resources required</li> <li>Monitor the impact and succes</li> </ul> </li> </ol>	
	Please refer to Annex 1 for a more detailed suggested steps that can be followed	

#### CAPACITY STRENGTHENING OF NETWORKS OF PLHIV

#### FOR:

- Sustainable resource mobilisation, including core funding
- Organisational strengthening and management
- Governance management and accountability
- Programme management and planning
- · Financial management and oversight
- Monitoring and evaluation
- Advocacy and communications
- · Responsiveness to the needs of key populations living with HIV
- · Evidence gathering, analysis and reporting
- Cross-border and multi-level linking, sharing and learning
- Leadership development and renewal
- Partnership development
- Community mobilisation
- Strategic activism

### TO ACHIEVE OUTCOMES:

- → Sustainable networks of people living with HIV that meet the needs of their constituents
- → Representative and meaningful participation of networks of people living with HIV in national coordinating bodies
- → Evidence-informed and constituent-driven networks of people living with HIV
- → Empowered and informed population of people living with HIV through greater participation in networks of people living with HIV
- → Greater efficiency and effectiveness of national programmes through the active and effective participation of networks of people living with HIV in programme planning, delivery and management
- → Enhanced coordination among networks and associations of people living with HIV within the country from all levels local community, district, province, and national levels

### SUGGESTED STEPS:

- 1. Map areas of support your or other organisations provide to strengthen the capacity of networks of PLHIV
- 2. Assess your organisation's ability to provide or past experience in providing support
- 3. Collaborate with networks of PLHIV to assess current gaps and strengths in support
- 4. Assess opportunities and bottlenecks
- 5. Take follow-up steps to improve and strengthen the capacity of networks of PLHIV
  - Advocate
  - Adapt current policies
  - Remove legal barriers
  - Mobilise resources and support
  - Provide guidance on reporting procedures
  - · Monitor and evaluate and share lessons learned

Please refer to Annex 1 for a more detailed suggested steps that can be followed

#### THE Y+ LEADERSHIP INITIATIVE

In response to the need for sustainable leadership among young people living with HIV (YPLHIV), GNP+ held a series of consultations under the auspices of the Y+ Programme (YPLHIV Programme) of GNP+. Electronic consultations, surveys, interviews and focus group discussions helped GNP+ map the leadership needs of YPLHIV; identify the key barriers to accessing tools, resources and learning opportunities; highlight the existing leadership programmes and initiatives in place; and learn from more established positive leaders of their experiences of leadership development.

These consultations led to a face-to-face expert meeting, where participants outlined a leadership initiative. The initiative would respond to the following needs highlighted by the consultations:

- The HIV response has professionalized and with it the leadership needs of the community have changed.
- There are several tools and resources for leadership capacity building but not managed or centralized in a common space for easy access and use.
- There is a collective responsibility from YPLHIV and all other stakeholders to commit efforts to building sustainable leadership within the positive community.
- YPLHIV need access to practical learning experiences as well as the wealth of expertise already within the community.

The Y+ Leadership Initiative is an electronic platform, whereby YPLHIV can access a centralized space for leadership capacity building resources and opportunities. The platform consists of a library, a learning directory, a mentorship scheme and a code of commitment. The library contains existing and adapted tools and resources that provide leadership capacity building for YPLHIV. The learning directory lists upcoming relevant learning opportunities (such as internships, workshops, fellowships, job vacancies, governance positions and conference scholarships) Under the Y+ Leadership Initiative Code, signatories commit to a set of principles and practical expectations to ensure that building the leadership capacity of YPLHIV is a collective responsibility.

In 2010, the national network of PLHIV of Tanzania, NACOPHA, began its collaboration with GNP+ and the Population Council to undertake operational research on Positive Health, Dignity and Prevention. NACOPHA engaged with the government of Tanzania as a research partner. That collaboration led to the revision and enactment of laws that protect the rights of PLHIV in the country using a Positive Health, Dignity and Prevention framework. In 2011, NACOPHA was a partner to the government's elaboration of the Tanzanian Positive Health, Dignity and Prevention Operational Guidance.

#### CÔTE D'IVOIRE:

#### USING THE "ADA PROCESS" TO ESTABLISH PLHIV ASSOCIATIONS IN HIGHLY STIGMATISING ENVIRONMENTS (2008-2010)

RIP+, a network of 50 PLHIV associations in Côte d'Ivoire, confronts stigma and discrimination as organizational challenges in its efforts to facilitate the establishment, support, and strengthening of new member associations and to empower individual PLHIV activists and leaders.

The "ADA Process" addresses stigma and discrimination on individual, organisational, and societal levels, promoting activism by and greater involvement of individual PLHIV in the response to HIV. Steps include:

- Situational analyses to identify context-specific challenges
- Ambassadors' missions to gain the support of local opinion leaders
- Management training for new members
- General assembly to formalize the association
- Joining the RIP+
- Strategic orientation training
- Ongoing coaching
- Securing financial and technical resources

The ADA Process increases involvement of PLHIV, including those with low literacy levels in rural areas (often left out of traditional approaches) as well as those who are highly educated (traditionally reluctant to disclose their status publicly). Using this process, RIP+ has helped to create four new local associations and enhanced the networking potential of the newly formed groups by facilitating a collaborative spirit among stakeholders. As a result, PLHIV play key roles in decisionmaking and service delivery in participating associations.

#### PLHIV LEGAL, RIGHTS AND HEALTH LITERACY FOR: Treatment access and adherence Prevention of HIV transmission, including treatment as prevention • Sexual health and comprehensive sexuality · Reproductive health and family planning human rights and local laws, including what legal and human rights services are available Healthy living with HIV • Self-empowerment, self-esteem and confidence TO ACHIEVE → Improved effectiveness and efficiency of treatment, prevention, care and support programmes for PLHIV **OUTCOMES:** → Greater access to treatment, prevention, care and support among PLHIV → Improved health outcomes for people living with HIV through self-management of one's health → Reduced human rights violations experienced by people living with HIV through greater access to legal protections and services → Improved contribution of people living with HIV to their communities through advocacy for and greater access to social justice and better health outcome 1. Collaborate with a network of PLHIV to assess the level and source of legal, rights and health **SUGGESTED** literacy of PLHIV STEPS: 2. Assess the level and source of literacy on legal, rights and health related to HIV among police, judges and legal advocates 3. Assess lessons learned, opportunities, challenges and successes 4. Take follow-up steps to improve legal, rights and health literacy of PLHIV • Gather evidence • Review and distribute legal rights and health literacy materials • Meaningfully involve networks of people living with HIV • Link networks of PLHIV with human rights and legal groups • Ensure that information targeted to PLHIV is accurate, age- and gender-appropriate, evidenceinformed, and culturally appropriate • Sensitise and train those who deliver information • Provide support for PLHIV • Advocate for protective laws and the reform of punitive laws • Monitor the impact • Sensitize police and get pragmatic agreements for their support of outreach programmes and service providers Sensitize judges and prosecutors to make informed and non-discriminatory decisions regarding HIV-related issues • Identify and work with a source of legal assistance/services for PLHIV

Please refer to Annex 1 for a more detailed suggested steps that can be followed

#### HEALTH PROMOTION AND ACCESS

Positive Health, Dignity and Prevention aims to improve the health outcomes of PLHIV through a combination of actions at the service, systemic and policy levels that accelerate scaling up the number of people who access health services, and also improve service quality and outcomes.

As with other components of Positive Health, Dignity and Prevention, the actions falling under the heading of health promotion and access are not 'new', but rather articulate a rationale for why providing not only HIV treatment services but a 'comprehensive set of health services' will improve outcomes. Moreover, health promotion and access will meet the comprehensive health needs of PLHIV, including but not limited to antiretroviral therapy (ART).

ART delivery must be accompanied by high-quality and regular clinical monitoring and adherence support services, as well as treatment literacy initiatives that empower PLHIV to know when and how to access treatment and how to manage side effects. ART regimens should be in accordance with WHO guidelines. ART regimens must be accessible to PLHIV, which may require overcoming barriers related to direct and indirect costs to the provider or the HIV-positive individual.

Care and support for PLHIV must combine physical, social, emotional and mental support. PLHIV must be supported in overcoming self-stigma, stigma and discrimination faced at home and in their communities and in health services; in dealing with their HIV infection; and in managing relationships with their families and loved ones. Effective bidirectional referral systems between health and social service sectors may result in efficiencies, but they must be functional, and the resulting services and support must be non-judgemental, relevant and rights-based.

Access to ART is not the only treatment need that PLHIV have. Tuberculosis (TB), for example, remains one of the most significant causes of mortality amongst PLHIV, demanding prompt diagnosis and treatment. Diagnostic and treatment services are similarly imperative for hepatitis C co-infections for people who use drugs living with HIV, and legal barriers to providing opiate substitution therapy must be overcome. In addition, ART is accompanied by side effects and can sometimes fail, underscoring the need for ongoing medical monitoring. Likewise, treatment services related to non-communicable diseases are also necessary for people living with HIV and must not be neglected.

#### HEALTH PROMOTION AND ACCESS

#### GOAL

Improved health outcomes for PLHIV through the provision of appropriate, inclusive, quality and sustainable treatment, care and support.

#### SUB-COMPONENTS

- Treatment access for PLHIV
- Care and support of PLHIV
- · Prevention, diagnosis and treatment of other infections and illnesses for PLHIV
- Quality assurance and improvement of health services for PLHIV

#### **EXPECTED OUTCOMES**

- · Improved health outcomes among PLHIV through early diagnosis, adherence to effective and appropriate treatment regimes, and treatment of opportunistic and co-infections
- Improved cost-effectiveness through efficient procurement and delivery treatment systemss

Moreover, the quality and sustainability of health promotion and access for PLHIV are critical priorities. In the absence of a cure for HIV, ART is a lifelong commitment. At the systemic level, actions must be taken to ensure that seamless, uninterrupted procurement of ART, elimination of stock-outs, and quality assurance for antiretroviral medicines (ARVs). Systemic actions are required to ensure cost-efficiency and -effectiveness of mechanisms procurement, distribution and delivery of drugs to the end user. Ongoing health-systems-strengthening is vital to effective provision of treatment, care and support. Furthermore, updated national guidelines must ensure continuous training opportunities for health care providers and include measures to reduce stigma, discrimination, lack of confidentiality and informed consent in clinical settings and means of addressing such human rights violations related to access to and the delivery of services.

This section pinpoints 'what' the expected elements and actions are under each area of health promotion and access, and offers examples of steps that may be taken to improve the level and quality of health promotion and access for PLHIV. National contexts may require different sets of steps, and not every country will follow the same path.

#### **KEY POPULATIONS LIVING WITH HIV**

With respect to health promotion and access, the particular needs of key populations living with HIV must be effectively addressed, and treatment and care should be tailored to their specific needs. For example, testing and counselling services for sex workers should be delivered in a manner that does not endanger the lives and livelihoods of workers who may be diagnosed as HIV-positive. Treatment for MSM living with HIV in settings where laws criminalise same-sex sexual relationships must be delivered in a way that does not place individuals at risk of prosecution or further social marginalisation. For people who use drugs living with HIV, services for ART and opiate substitution therapy (OST) should be tailored to each individual's specific needs, taking into consideration the impact of both OST and ART on their health. Young people living with HIV who access treatment, care and support often have needs that differ from adults, because of age-of-consent restrictions on health services or as a result of challenges they face in managing their health while seeking or maintaining employment. Moreover, adolescents living with HIV transitioning into adulthood

have specific medical, SRHR and psychosocial needs. Transgender people living with HIV require treatment and care that takes into consideration living with HIV in conjunction with hormonal therapies as well as genderrelated social drivers. In a broader context of gender inequality, women living with HIV require gender-responsive treatment services, antiretrovirals for themselves as well as for their babies, and care and support services that do not heighten their vulnerability.

Last but not least, children living with HIV require access to health services that address both HIV-related issues as well as other development and health-related issues. Without treatment, about half of the children will not live to see their second birthday. In addition, paediatric ARV formulations are not available in most areas of the world; few ARVs have been tested in children; and generic paediatric ARVs are not based on latest WHO guidelines. Moreover, parents and/or caretakers will require support related to when and how to disclose HIV status to the children.

#### COMPREHENSIVE HEALTH ACCES AND PROMOTION FOR PLHIV means ...

#### TREAMENT ACCES FOR PLHIV

- Testing and counselling with informed consent and confidentiality
- Timely and appropriate access to ART (including paediatric ARV formulations)
- Clinical monitoring
- Adherence support
- Treatment literacy
- Access to health care and insurance

#### CARE AND SUPPORT FOR PLHIV

- Palliative care
- Facilitated referral systems
- Facility and community-based interventions
- Mental and emotional health services
- Psychosocial services
- Counselling services and support groups
- Social protection (see also component on social protection)
- Family planning and support (see also SRHR component),





#### COMPREHENSIVE HEALTH ACCES AND PROMOTION FOR PLHIV means ...

#### PREVENTION, DIAGNOSIS AND TREATMENT OF OTHER INFECTIONS AND ILLNESSES FOR PLHIV

- Prevention of disease progression and further infections
- Prevention and treatment of side effects (e.g., heart diseases due to ART)
- Diagnosis, prevention and treatment of co-infections (TB, Hepatitis C)
- STI diagnosis and treatment
- OST for people who use drugs living with HIV
- Prevention and treatment of non-communicable illnesses (e.g., cardiovascular illnesses, lipodystrophy, cancers, etc.)
- Treatment of opportunistic infections
- Useful essential vaccines (e.g., Hepatitis B, pneumococcal, influenza vaccines, human papillomavirus, etc.)

#### QUALITY ASSURANCE AND IMPROVEMENT OF HEALTH SERVICES FOR PLHIV

- Age-, gender-, and culturally sensitive specific services
- · Monitoring of the quality and availability of services, including by PLHIV and community-based organizations
- Training and support of health care workers, including on infection control, non-discrimination, informed consent and confidentiality
- ART systems (procurement, delivery)
- Insurance schemes
- Monitoring compliance with WHO guidelines
- For marginalized populations, services provided that integrate treatment, health, legal and social support
- At the international level, this also includes...
  - · Research on long-term effects of ART
  - · Research on paediatric dosages

#### TO ACHIEVE **OUTCOMES:**

- → Improved health outcomes of PLHIV through early diagnosis, adherence to effective and appropriate treatment regimes, and treatment of opportunistic and co-infections
- → Improved cost-effectiveness through efficient procurement and delivery treatment systems

#### SUGGESTED STEPS:

- 1. Map programmes and services
- 2. Map coverage and determine gaps
- 3. Assess costs and resources available
- 4. Map and assess existing guidelines
- 5. Other evidence
- 6. Assess the success and challenges
  - Take follow-up steps
  - Share your work
  - Advocate
  - Meaningfully involve PLHIV and networks of PLHIV
  - Integrate
  - Mobilise political and organisational leadership
  - Demonstrate the impact of health access and promotion for PLHIV
  - Adapt current policies and remove legal barriers
  - Address stigmatising attitudes amongst health care workers, police and other service providers
  - Address gaps in coverage
  - · Review organisational and coordination management
  - Determine resources
  - · Monitor and evaluate

Please refer to Annex 1 for a more detailed suggested steps that can be followed

### PEOPLE LIVING WITH HIV DOCUMENT THEIR EXPERIENCES

#### IN THE CONTEXT OF SCALING UP ACCESS TO HIV TESTING AND TREATMENT IN SWAZILAND

The Swaziland Network of People Living with HIV (SWANNEPHA) led a study to document the experiences and perspectives of people living with HIV. Using the Positive Health, Dignity and Prevention framework, SWANNEPHA adapted a questionnaire that had been tested in Tanzania, Bolivia and Vietnam, to their local context. With the support of the Population Council, the Clinton Health Access Initiative and GNP+, SWANNEPHA developed and submitted a protocol that obtained ethical approval. The network organised a three-day training for data collectors, which involved a thorough review of the study questionnaire, a discussion about principles of research, and training on the use of personal digital assistant (PDAs) devices. Data collectors reported that it was an empowering process, which contributed to enhancing their research and technical skills.

The study involved 870 people living with HIV across the country. Participants were approached through 100 support groups and through expert clients based in 22 health facilities. A team of 10 data collectors, who were people living with HIV themselves, carried out face-to-face interviews using PDAs. Data collection occurred between December 2011 and February 2012. Participants included men (30%) and women (70%), individuals on ART (71%) and in the pre-ART stage (29%), from the four regions of Swaziland, in both rural (93%) and urban (7%) areas. The study generated several key findings:

- The majority of people living with HIV (53%) took an HIV test because they were ill or losing weight;
- 86% felt that stigma and discrimination (e.g., being seen to visit a health facility) and lack of food (43%) prevented them from taking ART;
- Among 156 people living with HIV who reported having ever forgotten to take their ARVs, the main reason was forgetting the medications at home (70%);
- Among 105 people living with HIV who said they had experienced some form of stigma and discrimination, the majority of instances occurred at social gatherings (34%) and amongst family (32%);
- 36% reported taking no action when confronted with instances of stigma and discrimination.

Documenting the experiences of people living with HIV is critical for informing strategies for implementing programmes and policies. Understanding the stigma and discrimination experienced by people living with HIV, their access to health services, and the socio-economic context helps identify, promote and improve services, which enable PLHIV to feel safe to seek HIV testing, to continue taking HIV treatment, to share responsibility for preventing HIV, and to lead healthy and productive lives.

#### **GENDER EQUALITY**

Positive Health, Dignity and Prevention requires specific actions to address issues of gender equality. Positive Health, Dignity and Prevention recognises that achieving gender equality requires actions that extend beyond the HIV response or in addition to actions specific only to PLHIV. However, for the purpose of this document, only actions specific to PLHIV are described, with the understanding that these actions should not replace national responses for gender equality for all, but that they must be carried out in combination with the broader work carried out at the national level to achieve gender equality.

For purposes of Positive Health, Dignity and Prevention, gender equality refers to equality for women and men of all sexual orientations, transgender and intersex people.

Centralised and systemic responses to achieve gender equality for PLHIV should include actions to reform or repeal laws and policies that undermine equality in relation to gender identity and sexual orientation, enactment of protective laws to protect against discrimination and violence, and systems for redress that respond to rights violations. Key actions include mobilising political will and leadership, supporting networks of key populations living with HIV to be active partners in reforms, and putting systems in place to monitor how law and policy are implemented. Actions also should include addressing gender-based and domestic violence - laws, policies, training of service providers and authorities, etc.

Service provision for gender equality for PLHIV should address the quality of services provided to PLHIV irrespective of sexual orientation and gender identity. To achieve gender equality in service access requires not only addressing disparities due to sex, but also imbalances and inequalities due to gender identities and sexual orientation. This may require training for service providers, addressing stigmatising attitudes amongst service providers, and addressing human rights violations such as the forced or coerced sterilisation of women living with HIV accessing services for the prevention of new infections in children (PMTCT), denial of family planning or sexual and reproductive health services for young women living with HIV (age-related restrictions as well as attitudes from service providers), gender-based violence, or the denial of treatment for transgender people and MSM living with HIV.

#### **GENDER EQUALITY**

#### GOAL

To ensure positive outcomes related to PLHIV's mental, social and physical health irrespective of their sexual orientation and gender identity To contribute to overall efforts at the national level aimed at reducing vulnerability to HIV due to sexual orientation and gender identity To contribute to overall efforts at the national level aimed at reducing vulnerability to HIV due to harmful gender norms, gender-based violence and unequal power relation

#### **SUB-COMPONENTS**

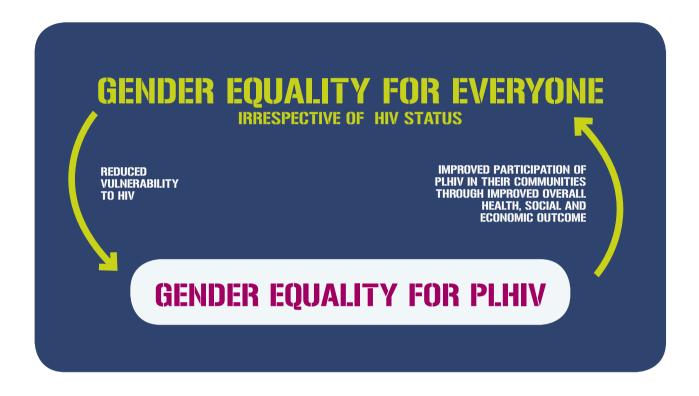
- Centralised and systemic responses
- Service provision
- Empowerment
- · Actions to address social and legal drivers

#### **EXPECTED OUTCOMES**

- Improvements in the level and quality of access to treatment, prevention, care and support for PLHIV through gender-responsive and -protective legal, policy and systemic structures and services
- · Reduced stigma and discrimination due to sexual orientation and gender identity in communities, service provision settings and systemic structures
- Improved participation of women, girls, MSM and transgender people living with HIV in their communities and in the response to HIV through empowerment and rights literacy

In addition to ensuring the quality of services, certain specific services need to be developed for women, girls, MSM and transgender people living with HIV. Women living with HIV often bear the burden of care because of their gender, underscoring the importance of initiatives that support care givers and alleviate their burdens. PMTCT programmes must be accessible and affordable for all women living with HIV. MSM and transgender people living with HIV may need to access specific services that are not integrated into general population services, such as hormonal therapy or treatment for other infectious diseases, partly because of the gender inequalities that exist in the community.

Individuals and communities must be empowered to



understand gender equality, their rights, and what services are available to ensure that their rights are protected through legal and health literacy. Networks of women living with HIV, MSM and transgender people are also critical in enabling change within communities as well as contributing as equal partners in community and national responses.

Gender equality for PLHIV also requires actions to address social drivers and ensure the participation and support of men (e.g., in PMTCT services). Actions for gender equality should be integrated into the work at the country level to address stigma and discrimination faced by MSM,

transgender people, sex workers and other key populations irrespective of their HIV status.

This section describes the expected elements and actions under each facet of gender equality, and provides suggested steps to improve the level and quality of gender equality for PLHIV. National contexts may require different actions, and will, therefore, necessitate the adaptation of the steps to ensure relevance and appropriateness.

#### **GENDER EQUALITY FOR PLHIV**

#### CENTRALISED AND SYSTEMIC RESPONSES

#### LEGAL REFORM (REFORMING EXISTING LAWS OR ENACTING NEW LAWS)

- Laws enshrining equal legal rights irrespective of sex, gender identity and sexual orientation
- Protective laws against gender-based violence (GBV)
- Decriminalisation of same-sex sexual relationships
- · Treating drug dependency as a health condition, not a crime, and decriminalizing possession of small amounts for personal use
- Legal protection for sex workers
- Legalisation of same-sex sexual relationships between consenting adults (decriminalisation of homosexuality and, where indicated, declassification of homosexuality as an illness)
- · Declassification of transgenderism as an illness and access to identity and social security systems for transgender
- Legal rights to access services irrespective of gender or occupation
- Reform inheritance laws to ensure equal rights

#### AND IN PARTICULAR FOR PLHIV

- · Decriminalisation of HIV non-disclosure, (perceived or potential) exposure and non-intentional transmission, in particular sexual transmission and exposure (see also components on SRHR and human rights
- · Responding to violence against women, MSM and transgender people living with HIV, as well as people who use drugs

#### LEGAL SERVICES AND THE ENFORCEMENT OF PROTECTIVE LAWS

 Develop, implement and monitor functioning grievance and redress mechanisms for those who have been victims of gender-related discrimination, GBV, and other human rights violations

#### AND IN PARTICULAR FOR PLHIV

- · Functioning systems that offer protective services to women living with HIV including lesbians, and MSM and transgender people living with HIV
- Addressing forced sterilisation of women living with HIV in sexual and reproductive health and PMTCT services
- Addressing violence against women, MSM and transgender people living with HIV

#### MOBILISATION AND ADVOCACY FOR SYSTEMIC AND LEGAL REFORM

- · Mobilisation of political will and leadership for legal reform and the enforcement of laws and protective legal service systems
- Mobilisation of civil society, networks and communities to advocate for reform and societal attitudinal change

#### AND IN PARTICULAR FOR PLHIV

- · Functioning systems that offer protective services to women living with HIV including lesbians, and MSM and transgender people living with HIV
- Addressing forced sterilisation of women living with HIV in sexual and reproductive health and PMTCT services
- Addressing violence against women, MSM and transgender people living with HIV

#### **SERVICE PROVISION**

- Support to and access to services for care givers
- Services for women, including family planning and other SRHR (e.g., maternal health, STIs, GBV)
- Training of service providers towards gender-responsiveness
- Referrals to social protection services and support
- GBV-related support services to victims of GBV

#### AND IN PARTICULAR FOR PLHIV

- · Support to care givers, in particular women caring for families and orphans and vulnerable children (OVCs) and in households with people living with HIV
- PMTCT programmes
- Training treatment service providers (e.g., gender sensitisation)
- Addressing forced sterilisation of women living with HIV in sexual and reproductive health and PMTCT services
- Training health care providers on sexual orientation and gender identity and transgender-specific health needs (e.g., hormonal therapy, plastic surgery, etc.)
- Developing or linking with existing services that respond to gender-based violence



#### **GENDER EQUALITY FOR PLHIV**

#### **EMPOWERMENT OF COMMUNITIES AND INDIVIDUALS**

- Rights and legal literacy
- Health literacy
- Education of those most vulnerable
- · Mobilisation of and support to networks of those most vulnerable, in particular women and key populations
- Economic empowerment of women
- Self-empowerment and decision making
- · Life skills, leadership training and self-esteem building of young women living with HIV

#### AND IN PARTICULAR FOR PLHIV

- Legal literacy for PLHIV, in particular women
- · Mobilisation of and support to networks of women living with HIV and key populations
- Self-empowerment and decision-making for PLHIV
- 'Know your rights' campaigns

#### SOCIAL DRIVERS AND GENERAL PUBLIC

- Sensitisation and awareness
- Mobilisation of communities
- Reduction or elimination of stigma and discrimination
- Engagement of men
- · Addressing cultural practices through community dialogue
- Reduction or elimination of homophobia and transphobia

#### AND IN PARTICULAR FOR PLHIV

- Reduction of stigma and elimination of discrimination against women, MSM, sex workers living with HIV
- Engagement of men in PMTCT and care giving

#### **SUGGESTED** STEPS:

- 1. Map areas where gender inequality and gender-based violence may be challenging for PLHIV
- 2. Review evidence of cases and the impact of rights violations and discrimination based on the sexual orientation and gender identity of PLHIV
- 3. Assess laws, policies, social and cultural practices that relate to gender equality and gender-based
- 4. Map existing evidence and efforts toward the achievement of gender equality and protection from gender-based violence
- 5. Assess the successes and challenges related to effective and rights-based reform.
- 6. Take follow-up steps to improve gender equality and freedom from gender-based violence of **PLHIV** 
  - · Advocate for reform to achieve gender equality and mobilise political, organisational and community leadership
  - Reach out to and involve the local network of women living with HIV and networks of key populations, in particular, MSM and transgender people.
  - · Review organisational management
  - Gather evidence
  - Adapt current policies, remove legal barriers and enact protective laws and policies
  - Operationalise protection services
  - Address stigmatising attitudes and discriminatory practices
  - Monitor progress and re-evaluate responses

Please refer to Annex 1 for a more detailed suggested steps that can be followed

#### MISSING THE TARGET 9

#### CAMEROON, CÔTE D'IVOIRE, ETHIOPIA AND NIGERIA

The International Treatment Preparedness Coalition (ITPC) studied four countries where gaps between need and access to prevention of vertical transmission services are among the largest. These countries also rank low on contraceptive use and have high fertility rates. The numbers of women using antenatal care (ANC) services, especially rural-dwelling and low-income women, are also low compared to other countries. In addition, young women in these countries are often several times more vulnerable to HIV than men, but lack access to knowledge and tools to prevent HIV. These related factors affect the effectiveness of PMTCT services for women.

Several barriers emerged as common themes in interviews conducted with affected women and health care workers in each of the four countries, including:

- Male partners are not involved in PMTCT services, missing an opportunity to be tested and treated, mainly due to an absence of policies and strategies to engage them.
- WHO guidelines on PMTCT and infant feeding are not being rolled out fully: sub-optimal single-dose nevirapine (sdNVP) is still used in two of the countries (Ethiopia and Nigeria), guidance on infant feeding is not clear and health care workers are not always supportive of exclusive breastfeeding (as recommended).
- Often ARVs are free, but costs of ANC, delivery, diagnostic tests, treatments for opportunistic illnesses (OIs) and sexually transmitted infections (STIs), and transportation to distant clinics are barriers for low-income women. In addition, drug stock-outs, especially for medicines for opportunistic illnesses, are common.
- Stigma, which is widely encountered in health care facilities, combined with a shortage of trained health care workers, long waiting times and lack of integrated services under one roof, discourage women from accessing ANC services, thereby missing opportunities for testing and treatment.

Source: ITPC. 2011. Missing the Target 9. The Long Walk: Ensuring comprehensive care for women and families to end vertical transmission of

A study of over 28,000 married women in India found that those who had experienced both physical and sexual violence from intimate partners were over three times more likely to be HIV-positive than those who had experienced no violence. Silverman JG et al., Intimate partner violence and HIV infection among married Indian women, Journal of the American Medical Association, 2008, 300(6):703-710.

A survey of women living with HIV in Argentina, Brazil, Chile and Uruguay in 2008 found that many had a history of violence, with 78.1% reporting experiencing some type of violence, 69.9% psychological violence from a partner, 55.6% physical violence, 36.3% sexual violence, and 32.8% sexual abuse in childhood.

FEIM; EPES; GESTOS; MYSU. HIV + Violence: two faces of the same reality. Violence against women and the feminization of HIV/AIDS in the MERCOSUR. Regional Fact Sheet. Bs. As. 2009.

Social change strategies may also reinforce measured changes in behaviour and incidence. For example, community-based participatory learning approaches may be effective in changing social gender norms, including violence, when HIV and violence prevention programming are paired with community mobilisation and engaging men to challenge harmful gender norms. A landmark study in South Africa recently suggested that nearly one in seven cases of young women acquiring HIV could have been prevented if the women had not been subjected to intimate partner violence.

Jewkes RK et al. Intimate partner violence, power inequity, and incidence of HIV infection in young women in South Africa: a cohort study. Lancet, 2010, 376:41-48.

#### **HUMAN RIGHTS**

Stigma, discrimination and human rights violations against PLHIV represent some of the most significant barriers to achieving universal access to prevention, treatment, care and support for PLHIV. Positive Health, Dignity and Prevention requires specific actions to address the human rights of PLHIV. Similar to gender equality, Positive Health, Dignity and Prevention recognises that promotion and protection of human rights extends far beyond work specifically focused on PLHIV alone. However, for the purposes of this document, only those actions specific to PLHIV are described, with the understanding that these actions should not replace national responses designed to achieve human rights for all but should be carried out in combination with the broader work at the national level.

Achieving human rights for PLHIV requires broader work on human rights in relation to HIV, including addressing the human rights of key populations (MSM, sex workers, people who use drugs, prisoners, transgender people, young people, etc.), broader work in achieving gender equality in the country, and the empowerment of young people. Actions under the component of human rights for Positive Health, Dignity and Prevention are informed by documented rights violations experienced by PLHIV, often because of overlapping gender inequalities; the criminalisation of drug use, same sex-sexual relationships, sex work; and inability to access services such as opiate substitution therapy. This document outlines actions specific to PLHIV within the context of the overarching social and legal drivers mentioned above.

Legal and policy reform and enforcement are essential to ensure the protection of the human rights of PLHIV. Whilst many endorse criminalisation of the malicious and intentional transmission of HIV under recognised legal principles, no rational basis exists for specific laws related to the criminalisation of HIV transmission or for the overly-broad criminalisation of nondisclosure, exposure or transmission where there no intent was present. Furthermore, criminalisation laws related to HIV transmission and exposure undermine the principles of shared responsibility and self-empowerment for one's own health. Individuals, irrespective of their HIV status, share equal responsibility for preventing as well as transmitting HIV. Reliance on coercive criminal laws only exacerbates vulnerabilities to HIV - in knowing one's HIV status and accessing testing, in prosecuting women living with HIV who may unwillingly transmit the virus to their babies, and in placing the responsibility on the 'other' and thus not taking preventive measures.

#### **HUMAN RIGHTS**

#### GOAL

The human rights of PLHIV are respected and protected through laws, law enforcement, access to justice and programmatic response People living with HIV are treated with dignity and respect in their families and communities

#### SUB-COMPONENTS

- Legal and policy reform and enforcement
- · Social change and empowerment
- Monitoring and responding to human rights violations

#### **EXPECTED OUTCOMES**

- Improved quality of lives of PLHIV and access to prevention, treatment, care and support services through human rights-based and protective legal, policy and systemic structures and services
- Less discrimination and fewer human rights violations faced by PLHIV through selfempowerment, rights literacy, and the monitoring and redress of rights violations

HIV-related restrictions on entry, stay and, residence ("travel restrictions" in short) also constitute violations of human rights, and concerted efforts must be taken to mobilise political will and leadership to repeal such laws. Likewise, access to prevention, treatment, care and support for PLHIV should be universal and recognised as an essential part of the human right to health. Each individual's HIV status must be confidential, particularly when an individual is HIV-positive. The decision to disclose one's status is the sole province of that individual - he or she alone should decide how, when and to whom to disclose his/her status.

Social change must be supported through the empowerment of PLHIV to know their rights and the laws that protect them and be able to confront the stigma, self-stigma and discrimination they face. Furthermore, PLHIV require the means to redress violations they face in their place of employment, in educational institutions, in accessing health services, and in their communities. Human rights violations against PLHIV should be monitored and addressed appropriately, including through functioning redress mechanisms, but also through evidence-gathering, target-setting, and community participatory action research. Evidence-gathering methodologies such as the PLHIV Stigma Index and Human Rights Count! offer opportunities for PLHIV to empower themselves and their communities

to know their rights; to understand how stigma manifests itself; to identify human rights violations faced by PLHIV in accessing health, employment or educational opportunities; and to enable national responses that implement evidenceinformed policies and programmes to reduce stigma and eliminate discrimination and rights violations.

This section describes the expected elements and actions under each area of human rights, and offers a set of steps to improve the human rights situation for PLHIV. National contexts may require different sets of activities, and thus not every country will follow the same path. Furthermore, communities and service providers should be sensitised and supported through training and guidelines to enable a change of attitudes and deliver rights-based services. Throughout the work on human rights for Positive Health, Dignity and Prevention, the responsiveness to key

populations living with HIV is of particular importance. The overlapping vulnerabilities of being HIV-positive and marginalised or facing gender inequalities are particularly acute for key populations. Women living with HIV, for example, face heightened human rights violations in forced and coerced sterilisations and denial of services (health, legal, protection, education, job opportunities, job promotion etc.), transgender people and MSM living with HIV are often denied access to treatment, and sex workers living with HIV frequently face abuses by police authorities and are denied access to treatment or access to services for their families.

#### PROTECTING THE HUMAN RIGHTS OF PLHIV means...

#### LEGAL AND POLICY REFORM AND ENFORCEMENT on...

- Decriminalisation and protection of rights for same-sex sexual relationships
- Legal recognition of sexual orientation and gender identities
- Sex worker rights
- OST provision for people who use drugs
- Elimination of forced sterilisations
- SRHR (e.g., maternal health, family planning, STIs, GBV)
- Gender equality
- · Access to employment, education, and health for all
- Human rights irrespective of HIV status, gender, drug use or other vulnerabilities (i.e. embed the rights of PLHIV in the rights for all)

#### AND IN PARTICULAR FOR PLHIV

- Remove overly broad laws criminalizing nondisclosure, exposure and transmission
- Train prosecutors and judges on science and medicine relating to HIV transmission, effects of treatment and living positively with HIV
- Remove HIV-related restrictions on entry, stay and residence
- Ensure confidentiality, safe disclosure and informed consent
- Ensure access to treatment, prevention, care and support
- Ensure rights of PLHIV in general

#### SOCIAL CHANGE AND EMPOWERMENT through...

- Actions to reduce stigma and eliminate discrimination towards HIV
- Community programmes
- Support for networks and civil society for advocacy and community mobilisation
- Educational programmes (e.g. HIV-sensitive rights programmes)
- Actions to reduce stigma and eliminate discrimination towards HIV
- Community programmes





#### PROTECTING THE HUMAN RIGHTS OF PLHIV means...

#### SOCIAL CHANGE AND EMPOWERMENT through...

- Support for networks and civil society for advocacy and community mobilisation
- Educational programmes (e.g. HIV-sensitive rights programmes)
- Actions to reduce stigma and eliminate discrimination directed at key populations

#### AND IN PARTICULAR FOR PLHIV

- Ensure legal and rights literacy
- · Reduce stigma and eliminate discrimination faced by PLHIV
- Reduce or eliminate self-stigma
- Create support groups
- Sensitisation on shared responsibility
- Reduce stigma and eliminate discrimination a towards key populations living with HIV

#### MONITORING AND RESPONDING TO HUMAN RIGHTS VIOLATIONS by...

- Gathering evidence
- Putting into place systems to record, monitor and respond to cases of rights violations
- · Putting into place and operationalizing systems of redress
- Training service providers
- Supporting networks of PLHIV to function and monitor

#### **SUGGESTED** STEPS:

- 1. Map current laws, policies and programmes
  - Criminalisation, punitive and restrictive laws
  - · Punitive law enforcement
  - Protective Laws
- 2. Map actions for reform and revision
- 3. Map stakeholders and partners
- 4. Gather and analyse evidence
- 5. Identify challenges to and opportunities for positive change
- 6. Take follow-up actions
  - Share your findings
  - Determine and/or mobilise the resources
  - Advocate
  - Mobilise political and organisational leadership
  - · Adapt and reform current policies and laws
  - Remove legal barriers
  - Reach out to others who have been engaged in addressing human rights violations of PLHIV and share lessons learned
  - Address stigmatising attitudes and discriminatory practices
  - · Document cases and the impact of human rights violations and respond to violations by taking
  - · Review the organisational management
  - Monitor progress and evaluate the success
  - · Partner with human rights and legal groups
  - Advocate with the National Human Rights Institution

Please refer to Annex 1 for a more detailed suggested steps that can be followed

#### PREVENTION OF NEW INFECTIONS

The prevention of new infections represents the component of Positive Health, Dignity and Prevention that reflects the greatest shift from past work on 'positive prevention'. Previous prevention-related efforts among PLHIV ('positive prevention' or 'prevention with positives') focused mainly on the prevention of new infections of HIV through the engagement of PLHIV to prevent HIV transmission to their partners, often in isolation or in the absence of other prevention efforts that engender shared responsibility for transmission and exposure. Positive Health, Dignity and Prevention provides a more holistic approach to prevention for PLHIV, articulating the broader prevention needs of PLHIV – that is, support for sero-discordant couples, prevention within the context of treatment for prevention, prevention within the context of criminalised behaviours, access to education (prevention literacy) that does not target only the HIV-negative population, and access to prevention technologies and treatment.

In other words, the prevention of new infections within the context of Positive Health, Dignity and Prevention begins with focusing on the well-being of PLHIV as the overarching goal, rather than focusing on the prevention of new infections being the sole goal and starting point.

Unlike previous approaches that separated prevention programmes for HIV-negative and HIV-positive individuals, Positive Health, Dignity and Prevention takes an approach allowing for the synergistic overlap of programming.

Education for HIV prevention that is targeted to the general population must be reviewed to reach everyone regardless of their known or perceived HIV status. The concept of shared responsibility for HIV prevention, and self-empowerment to manage one's health, must be the driving force for such education and prevention literacy programmes, primarily because undiagnosed HIV drives HIV epidemics and HIV-related stigma has a powerful effect on honest and open discussions of HIV risk. Perceptions of responsibility for HIV prevention must shift from the (diagnosed) HIV-positive person alone to both parties involved in consensual sex – because HIV is not only transmitted, it is also acquired. Furthermore, due to the impact of ART on individual infectiousness, when one knows his or her HIV-positive status, prevention literacy must be embedded into treatment literacy, counselling, and other services provided to PLHIV as they seek treatment, care and support.

#### **SWAZILAND**

### PLHIV STIGMA INDEX- SRHR-RELATED EVIDENCE

The People Living with HIV Stigma Index was rolled out in Swaziland in 2010. The in-country partnership included the Swaziland Network of People Living with HIV/AIDS (SWANNEPHA), Family Life Association of Swaziland (FLAS), UNAIDS, UNFPA, GNP+, ICW and the Ministry of Health. People living with HIV were at the centre of the process as interviewers, interviewees and data collectors, and they also analysed the data and compiled the final report.

Using a questionnaire adapted for use across Swaziland, 1,233 people living with HIV were interviewed: 74.3% (916) females, 25.3% (312) males and 0.4% (5) who identified themselves as transgender. A majority (75.8%) of interviewees lived in rural areas, 22.5% lived in small towns and 1.7% lived in cities. The interviews took place in the second half of 2010.

These interviews yielded the following results:

- Only 52.2% of the respondents had received counselling regarding their reproductive options since being diagnosed as HIV-positive.
- About 12.2% were advised by a health care professional not to have a child since they were diagnosed as HIV-positive. 3% of those interviewed were coerced into being sterilized.
- 5.8% of interviewees stated that their ability to obtain ART was conditioned on the use of certain forms of contraception.
- 1% of the respondents were coerced by a health care professional to terminate a pregnancy because of their HIV
- 10.2% were coerced by a health care professional in relation to a method of giving birth because of their HIV status.
- 17.3% felt that they were coerced with regard to infant feeding practices.

Another area that must merge from prevention efforts that were once separated for HIV-positive and HIV-negative populations is access to prevention technologies. Like the rest of the population, people living with HIV also require access to condoms, clean needles and other means of prevention. People living with HIV have the right to continue enjoying their sexual and reproductive health and rights, and they also have to the right to reduce harm from infections acquired through injecting drug use (for reducing the risk of transmission of HIV as well as of acquiring coinfections such as Hep C). Where prevention technologies are provided to PLHIV who know their HIV status, such provision must be non-judgmental and avoid coercion to prevent PLHIV from enjoying their SRHR.

All pregnant women living with HIV must have access to PMTCT measures. Women have the right to access such services without fear of being coerced to terminate pregnancies. Moreover, PMTCT must be embedded within life-long access to treatment, care and support that does not cease once the baby is delivered. Access should be aimed both at improving the health outcomes of the infant as well as ensuring the life-long care and support of the mother, recognising both the mother's independent human right to health and the fact that the mother's heath also affects the health of her infant.

Within the context of treatment as prevention, treatment should remain first and foremost intended for the improvement of health outcomes for PLHIV. The impact of treatment on prevention is an important outcome that is hailed by PLHIV as a breakthrough, but should be viewed as an additional beneficial outcome of treatment, not the primary purpose of treatment. Nonetheless, the preventive effects of treatment must be acknowledged and leveraged as new momentum for scaling up treatment access for PLHIV in a rights-based, age-specific, gender-responsive, culturally-appropriate and evidence-informed approach.

As more PLHIV know their status, and as more couples know of their sero-discordant status, it is important to provide support within a context of shared responsibility, through the provision of accurate information on prevention and treatment as prevention, and counselling and psychosocial support in the management of HIV-infection within the household. Furthermore, in some settings preexposure prophylaxis (PrEP) may be indicated (e.g., samesex sero-different couples in some settings[15]) as likely to be the first and most useful option.

#### PREVENTION OF NEW INFECTIONS

#### GOAL

To reduce the number of transmissions of HIV through the empowerment of PLHIV in accessing treatment and prevention within a context of shared responsibility for transmission and exposure

#### SUB-COMPONENTS

- · Comprehensive education that fosters shared responsibility
- Access to prevention technologies
- Access to PMTCT services
- Access to ART and treatment for prevention
- Support for sero-different couples

#### **EXPECTED OUTCOMES**

- · Improved sense and understanding of the shared responsibility for transmission and exposure among HIV-positive and HIV-negative populations
- · Increased access to condoms, clean needles, ART, and new and other prevention technologies amongst PLHIV
- · Reduced vertical transmission through the expanded access to PMTCT
- · Reduced number of transmissions through scaledup treatment access for PLHIVprocurement and delivery treatment systems

As with other aspects of Positive, Health, Dignity and Prevention, the needs of key populations living with HIV must be addressed with respect to prevention efforts. Sex workers living with HIV who risk losing their livelihoods or endanger their lives in disclosing their HIV status require prevention programmes that are responsive to their levels of vulnerability. People who use drugs living with HIV need specific programmes for prevention related to both injecting drug use as well as sexual transmission. MSM living with HIV in the context of the criminalisation of same-sex sexual relationships must be able to access prevention without fear of being persecuted. Finally, women and young people living with HIV must have access to gender-responsive and age-specific services.

<sup>15</sup> See for example the WHO guidelines which are forthcoming at the time of

## (PMTCT)) comprises of a package of interventions summarised as 4 pillars, which must be implemented simultaneously.

- Pillar 1: Primary prevention of HIV in women of childbearing age (with special emphasis on pregnant and breastfeeding women)
- Pillar 2: Prevention of unintended pregnancies in women living with HIV (as part of rights-based sexual and reproductive health (SRH) of people living with HIV)
- Pillar 3: Prevention of HIV transmission from women living with HIV to their infants using
- Pillar 4: Provide appropriate treatment, care and support to mothers living with HIV, their children, partners, and families

#### **SWAZILAND**

#### INCREASING AWARENESS ABOUT THE REPRODUCTIVE RIGHTS OF WOMEN LIVING WITH HIV

Service providers from all sites reinforce the Ministry of Health's commitment to support the rights of people living with HIV to have children. This principle is clearly stated in the country's national ART registration form, which records the 'child wish' of individuals on ART. Further discussions are held with HIV-positive clients at the clinic regarding the importance of informing the health care provider about their intention to get pregnant.

PMTCT service sites develop partnerships with the national network of PLHIV – SWANNEPHA – and mothers2mothers, and request their representatives to provide additional input to the clinic's HIV-positive clients about reproductive rights, fertility intentions and related decision-making.

Mentor Mothers from the mothers2mothers programme are identified as a definite advantage by health professionals. Mentor Mothers are HIV-positive mothers who provide peer education and counselling to HIV-positive pregnant women, and accompany clients from one service site to the next in large clinics. Not only do they perform these crucial functions, but their very presence is perceived to reduce HIV-related stigma and discrimination.

A Mentor Mother can spend an hour counselling a mother – time which a doctor does not have. In addition to mentoring and supporting other HIV-positive women through the PMTCT process, they also form part of a local team of community volunteers associated with FLAS. These community volunteers undertake outreach to reduce HIV-related stigma among local community members and encourage people who require treatment – such as ART – or SRH counselling to attend the FLAS clinic.

Mothers 2Mothers now operates in seven countries with 609 programme sites and has 1,499 HIV-positive women working as Mentor Mothers. The Mentor Mothers are treated as staff, receiving pay and additional weeks of training. They have a formal role in supporting health systems and in training clients. In 2011 alone, Mothers 2Mothers reached 242,000 pregnant women and new mothers living with HIV.

Sources: WHO, UNFPA, UNAIDS, IPPF. 2012. Gateways to Integration: A case study from Swaziland

The Inter-agency Task Team for Prevention and Treatment of HIV Infection in Pregnant Women, Mothers and their Children. 2011. Preventing HIV and Unintended Pregnancies: Strategic Framework 2011-2015

For more information on mothers2mothers approach, success and work in 7 countries can be found at: www.m2m.org

## PREVENTION OF NEW INFECTIONS

## **GENERAL POPULATION. INCLUDING HIV-NEGATIVE AND PLHIV** WHO DO NOT KNOW THEIR HIV STATUS

- **PLHIV** WHO KNOW THEIR HIV STATUS
- 1. Education that does not assume one is HIV-negative (this includes prevention and transmission literacy, human rights, empowering shared responsibility for transmission and prevention, elimination of stigma and discrimination, etc.)
- 2. Access to ART, condoms, OST, clean needles and other means of prevention
- 3. New prevention technologies (for specific key populations – guidance forthcoming for PrEP; upon scientific validations, timely issuance of guidance for microbicides)
- 4. Male circumcision for reducing the risk of HIV acquisition
- 5. Post-exposure prophylaxis
- 6. Testing and counselling (non-judgmental, voluntary, and rights-based; and not primarily for prevention)
- 7. Targeted social and behavioural change communication

- 1. Education that does not assume one is HIVnegative (this includes prevention and transmission literacy, human rights, elimination of stigma and discrimination empowering shared responsibility for transmission and prevention, etc.)
- 2. Access to condoms, OST, clean needles and other means of prevention
- 3. PMTCT for all who need it
- 4. ART and treatment for prevention
- 5. Support for sero-different couples (including PrEP for same-sex sero-different couples in some settings

#### PREVENTION OF NEW INFECTIONS

## SUGGESTED STEPS:

- 1. Assess priority areas of prevention for PLHIV with their meaningful engagement to ensure that priorities are determined by and for PLHIV
  - For the prevention of sexual transmission
  - For the prevention of injecting drug use- and other substance misuse—related transmission
  - For the prevention of vertical transmission
- 2. Assess level and quality of programmes delivering prevention for PLHIV
- 3. Map and analyse the national policies and guidelines related to access to prevention
- 4. Assess how 'shared responsibility' for prevention and transmission is developed
- 5. Assess successes and challenges faced by PLHIV in accessing prevention
- 6. Monitor level and quality of the involvement of people living with HIV in prevention programmes
- 7. Take follow-up steps to improve the level and quality of the prevention of new infections

  - Reach out to and engage the local network of people living with HIV
  - Mobilise political and organisational leadership
  - Remove legal barriers
  - Adapt current policies and programmes
  - Integrate prevention into SRHR, harm reduction, education, and health access programmes
  - Train and sensitise service providers
  - Involve PLHIV at all stages
  - Address stigmatising attitudes and discriminatory practices

Please refer to Annex 1 for a more detailed suggested steps that can be followed

## SEXUAL AND REPRODUCTIVE HEALTH AND **RIGHTS**

SRHR for Positive Health, Dignity and Prevention cannot be dissociated from programmes to achieve SRHR for the general population and must be embedded within general population programmes. These guidelines focus on SRHR programmes for PLHIV but recognise that these programmes cannot be delivered in isolation from programmes for the general population, but must be implemented in conjunction with them.

With the majority of HIV infections globally occurring through sexual transmission, ensuring the sexual and reproductive health and rights of PLHIV is not only important in terms of the ability of PLHIV to access their human rights, but it also has a major impact on preventing new infections.

For their sexual health and wellbeing, PLHIV require access to services related to the diagnosis and treatment of STIs and other sexual health illnesses, comprehensive sexuality education and counselling, and other services integrated into sexual and reproductive health (SRH) and HIV-related services where and when appropriate. Existing policies and guidelines should be reviewed – and, where indicated, revised – to ensure that services are age-specific and gender-responsive, that they respond to the full range of SRHR needs of PLHIV, and that service providers receive adequate training and sensitisation to provide these services through a non-judgemental and rights-based approach.

In addition, reproductive health for PLHIV requires access to PMTCT for mothers and their partners, with services integrated in accessible maternal health programmes, other reproductive health services, and other health services, such as those for cervical, breast, prostate and other relevant types of cancers and illnesses. Family planning services should include services related to infertility, including the prevention and treatment of STIs. Services must be provided within a human rights framework without fear of forced or coerced sterilisation or without fear of being discriminated due to age, gender identity, sexual orientation or ethnic group. Where human rights violations occur they, must be addressed in a timely and appropriate manner.

SRHR support for PLHIV includes not only genderspecific and age-responsive services for PLHIV, but also services, policies and laws that address sex and sexuality (these maybe embedded within the broader response to HIV including education for the general population).

## SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS

#### GOAL

To ensure the sexual and reproductive health and rights of PLHIV through human rights-based, age-specific and genderresponsive services and SRHR literacy

#### SUB-COMPONENTS

- · Sexual health and wellbeing
- Reproductive health
- Sex and sexuality
- Sexual and reproductive health and rights as human rights

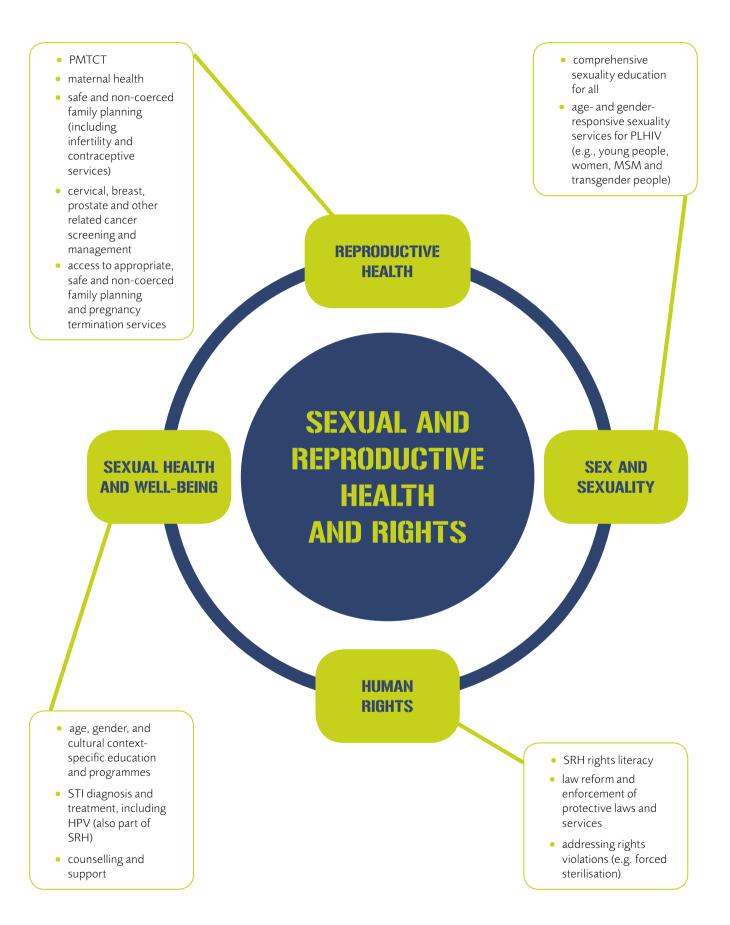
#### **EXPECTED OUTCOMES**

- · Improved sexual health and well-being, including a satisfying sex life, for PLHIV through agespecific, gender-responsive, culturally-appropriate and evidence-informed education and services
- Improved health outcomes for women and men living with HIV through increased access to comprehensive sexuality education and quality and rights-based sexual and reproductive health services
- · Reduced stigma and discrimination towards PLHIV due to sexual orientation and gender identity including through comprehensive sex and sexuality education for all and gender-responsive services

(see also components related to gender equality and human

Comprehensive sex and sexuality education must be provided through schools as well as within community settings. In addition, young people living with HIV must be supported through the provision of appropriate and specific programmes on their sex and sexuality as they transition into adulthood.

Sexual and reproductive health and rights for PLHIV should also be embedded within the broader work aimed at achieving SRHR as a part of human rights for all. Individuals should have access to sexual and reproductive health and rights literacy irrespective of their HIV status, and legal frameworks should be reviewed and reformed so that they address and remove the criminalisation of sexual orientation and non-disclosure, transmission and exposure to HIV. Protective laws need to be in place (laws that protect the SRHR of PLHIV, including key populations living with



#### SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS

### **SUGGESTED** STEPS:

- 1. Assess priority areas of SRHR for PLHIV through their meaningful engagement to ensure that priorities are determined by and for PLHIV
  - · Sexual health and well-being
  - Reproductive health
  - Sex and sexuality
  - Human rights
- 2. Assess level of integration of SRHR services in HIV-related programmes and vice versa
- 3. Take follow-up steps to improve level and quality of SRHR

  - · Engage the local network of people living with HIV, women living with HIV, and key populations
  - Mobilise political, organisational and community leadership
  - Remove legal obstacles and adapt current policies and programmes
  - Review programmes and guidelines
  - As much as possible or needed, integrate SRHR and HIV-related programmes
  - Train and sensitise service providers
  - Involve PLHIV at all stages
  - Address stigmatising attitudes and discriminatory practices
  - Monitor both the level and quality of programme

Please refer to Annex 1 for a more detailed suggested steps that can be followed

HIV). Where human rights violations occur, they should be addressed; functioning redress mechanisms should be created or strengthened to respond to forced sterilisations and other SRHR-related human rights violations.

Particular attention must be paid throughout all programmes of SRHR for Positive Health, Dignity and Prevention to key populations living with HIV. Sex workers living with HIV who are more vulnerable to exposure to STIs, for example, must be able to receive diagnosis and treatment without the danger or fear of losing their livelihood or experiencing violations of their human rights. Programmes must have the capacity to address issues of sexual orientation and gender identity, and ensure that the rights of MSM living with HIV can be achieved through the provision of sexuality education that is gender-responsive and -sensitive. The training and sensitisation of those who provide support to

MSM living with HIV should be accompanied by broader efforts to reduce stigma, eliminate discrimination against MSM, and remove laws that criminalise same-sex relations. Women and girls living with HIV must be empowered to make decisions regarding their own lives and sexuality and negotiate condom use at the same time as efforts continue to engage men in changing cultural norms related to gender inequality. Young people living with HIV require access to SRHR-related education that does not assume the audience is HIV-negative. HIV-positive young people need specific support for SHRH; for example, providing support and guidance to a young person living with HIV who has lived with HIV throughout their life as they enter into adulthood requires specific services to allow them to come to terms with their sexuality.

#### SOCIAL AND ECONOMIC SUPPORT

Social and economic support for PLHIV within the context of Positive Health, Dignity and Prevention is perhaps the most difficult to address, as it depends in large measure on the broader national economic, social and social protection systems, which are often overburdened and underfinanced. This component challenges strengths and capacities of 'systems' such as those that provide employment, health and social services, and food security. Nonetheless, it is arguably the component in Positive Health, Dignity and Prevention that most influences the degree to which PLHIV are able to participate fully and meaningfully in the economic and social empowerment of their communities and countries.

Employment and economic empowerment for PLHIV—in particular, women and young people living with HIV requires ensuring that PLHIV have equitable access to education and employment. Workplace policies and laws should ensure the rights of PLHIV, and partnerships between networks of PLHIV, trade unions, employers' coalitions and ministries of labour should work together to ensure harmonisation of policy and action at the local level and in the workplace. Women and young people living with HIV, who are more vulnerable because of their gender and age as well as their HIV status, need support through focused education and employment opportunities, such as facilitating access to micro-financing, (re-) training opportunities, income generating activities, apprenticeships and job placement, and vocational training.

Social protection for PLHIV has until now mainly been limited to a few programmes providing cash transfers and support for households with an HIV-positive person. with the aim of ensuring access to education for children belonging to such families. There is now a concerted effort at the international level to review the response to HIV from the social protection 'sector' and to develop guidelines for a 'comprehensive, HIV-sensitive' social protection response<sup>[16]</sup>. Efforts are also underway to develop ethical guidelines for care workers serving key populations and their families<sup>[17]</sup>. While awaiting the introduction of such guidelines, however, progress must not stall. Rather, national-level efforts must continue to improve the social protection of PLHIV and to inform international guideline formulations. Social protection programmes should be reviewed to ensure that PLHIV have equal access. Functioning referral systems between health and social services are required to ensure access to services and promote efficiency of costs and resources. To address HIVrelated stigma, discrimination and human rights violations,

#### GOAL

PLHIV are able to participate fully and meaningfully in the economic and social empowerment of their communities

#### SUB-COMPONENTS

- Employment and economic empowerment
- Social protection
- Support for caregivers
- · Healthy living conditions

#### **EXPECTED OUTCOMES**

- · Improved health outcomes of PLHIV and their families
- Strengthened participation of PLHIV in their communities (economic and social participation)
- Decreased stigma and discrimination in services for PLHIV
- · Strengthened communities (economically and social cohesion)

social protection should be linked to legal and protective services that effectively identify rights violations and put into place actions to restore the rights for the person living with HIV.

Evidence from the PLHIV Stigma Index indicates that households led by people living with HIV include significantly disproportionate numbers of orphans due to AIDS[18]. In addition to support for PLHIV as caregivers, support to PLHIV also requires support for those giving care to them. Social support for care giving includes nutritional support, exemption from school fees, access to health and HIV services, tutorial and psycho social support for orphans and vulnerable children, and ensuring access to pensions for grandmothers and elderly people caring for extended households because of HIV.

The need to ensure food and water security assumes particular importance for PLHIV. Food, livelihood and water security programmes must reach PLHIV households and communities affected by HIV, as PLHIV are more susceptible to unhealthy environments due to their compromised immune systems. PLHIV are also more susceptible to loss of housing due to illness and their inability to work during an illness. Ensuring that housing security is maintained will allow PLHIV to improve their health outcomes in a safe and protective environment and to participate as equal partners in strengthening their community.

SOCIAL AND ECONOMIC SUPPORT

<sup>16</sup> UNAIDS UBRAF 2012-2015

<sup>17</sup> Collaborative effort between CCABA, UNAIDS, International HIV/AIDS Alliance, MSMGF, INPUD, NSWP, GNP+ (expected completion end of 2012)

<sup>18</sup> PLHIV Stigma Index reports from Kenya and Zambia (NEPHAK and NZP+, respectively; 2010)

#### SOCIAL AND ECONOMIC SUPPORT FOR PLHIV means...

## EMPLOYMENT AND ECONOMIC EMPOWERMENT through...

- Access to full education, skills training and employment opportunities for PLHIV, in particular, YPLHIV
- Further education and retraining opportunities for PLHIV, in particular, YPLHIV
- Support of productive financial service linkages including cooperatives for women in particular
- Access to pension

## MONITORING AND RESPONDING TO HUMAN RIGHTS VIOLATIONS by...

- Gathering evidence
- Putting into place systems to record, monitor and respond to cases of rights violations
- Putting into place and operationalizing systems of redress
- Training service providers
- Supporting networks of PLHIV to function and monitor

# SUGGESTED STEPS:

- 1. Map current laws, policies and programmes
  - Criminalisation, punitive and restrictive laws
  - Punitive law enforcement
  - Protective Laws
- 2. Map actions for reform and revision
- 3. Map stakeholders and partners
- 4. Gather and analyse evidence
- 5. Identify challenges to and opportunities for positive change
- 6. Take follow-up actions
  - Share your findings
  - Determine and/or mobilise the resources
  - Advocate
  - Mobilise political and organisational leadership
  - Adapt and reform current policies and laws
  - Remove legal barriers
  - Reach out to others who have been engaged in addressing human rights violations of PLHIV and share lessons learned
  - Address stigmatising attitudes and discriminatory practices
  - Document cases and the impact of human rights violations and respond to violations by taking actions
  - · Review the organisational management
  - Monitor progress and evaluate the success
  - Partner with human rights and legal groups
  - Advocate with the National Human Rights Institution

Please refer to Annex 1 for a more detailed suggested steps that can be followed

DEVELOPING ETHICAL GUIDELINES FOR CARE WORKERS IN PROVIDING CARE TO KEY POPULATIONS AND THEIR FAMILIES (EXPECTED COMPLETION END OF 2012)

COLLABORATIVE EFFORT BETWEEN: CCABA, UNAIDS, INTERNATIONAL HIV/AIDS ALLIANCE, MSMGF, INPUD, NSWP, GNP+

To inform the development of ethical guidelines for care workers serving key populations and their families, partners developed and disseminated a survey for care workers (those who provide services) and key populations (those who receive services). Survey results gathered to date include the following:

- Over 70% of survey respondents said that care workers face ethical dilemmas at least monthly when providing HIVrelated care, support, and/or advocacy to households affected by HIV. The most commonly identified sources of ethical dilemmas are "client safety" and "conflicting client/ organizational expectations".
- Ethical dilemmas negatively affect both care workers and persons receiving care. Ethical dilemmas decrease the quality of services, erode trust between care workers and persons receiving care, and lead to moral distress.
- The most common methods used to handle ethical dilemmas are: thinking about the interests and human rights of all the adults and children involved; and talking to peers, including colleagues, family and friends.
- Care workers with written guidance are more confident in their own and their organization's ability to handle ethical dilemmas than care workers without written guidance.
- Care workers without written guidance were less likely to agree that they need to learn more about ethics than those with written guidance.
- Care workers and persons receiving care thought that more training on ethics is necessary for care workers to be able to handle ethical dilemmas. Care workers also identified the need for a decision-making framework for working through ethical dilemmas
- Overall, care workers and persons receiving care feel that care workers need more help handling ethical dilemmas. Almost all of the care workers surveyed agreed that they need to learn more about ethics and how to use tools for ethical decision-making. Care workers and persons receiving care say that written guidance will help workers handle ethical dilemmas.

Source: Kimberley Ibarra and Sally Qi. 2012. Care workers guidance project: Consultation survey results.

#### **MEASURING IMPACT**

Measuring impact is an essential component of Positive Health, Dignity and Prevention. It is essential to avoid losing impact evaluation in the overall delivery of programmes due to the over-extended workloads of service providers, absence of simple and easy-to use monitoring and evaluation (M&E) guidelines and mechanisms, and limited resources.

Impact measurements, as well as recording and sharing the lessons learned to inform evaluations, provide evidence for programmatic adaptations and support others as they develop new programmes - key considerations in all components of Positive Health, Dignity and Prevention (see sections 2.a to 2.g above). Several specific overarching actions can support monitoring the impact and learning from diverse experiences.

It is important to note that these guidelines address social transformation, which is among the hardest indicators to measure or to change<sup>[14]</sup>.

## MEASURING IMPACT

#### GOAL

To ensure effective and efficient policies, strategies and programmes for PLHIV through the continuous learning and adaptation based on capturing evidence and the lessons learned.

#### SUB-COMPONENTS

- Developing good policy and practice (through systematic monitoring progress and impact)
- Generating and applying evidence (with PLHIV leadership and meaningful involvement)
- Development and adaptation of indicators (not only at national level)
- Resources for monitoring and evaluation (and adapting programmes based on evidence and lessons learned)

#### **EXPECTED OUTCOMES**

- IProgrammes and policies are evidence-informed and based on lessons learned in the country
- Programmes and services are scaled-up based on in-country experience and evidence
- Policies, programmes and services are efficient and effective, and appropriate to the actual needs of PLHIV
- Improved monitoring and evaluation and effective adaptation based on appropriate indicators and costed and resourced M&E plans
- Improved accountability

## **MEASURING IMPACT**

## **SUGGESTED** STEPS:

- 1. Map sources of evidence, M&E guidelines, and frameworks and processes,
- 2. Assess gaps and strengths of indicates
- 3. Assess successes and challenges related to reporting and accountability mechanisms
- 4. Develop a comprehensive and inclusive M&E framework
- 5. Support PLHIV-driven evidence gathering and the meaningful participation of PLHIV in M&E
- 6. Continuously learn from good policy and practice

Please refer to Annex 1 for a more detailed suggested steps that can be followed

<sup>14</sup> Refer also to the component of sexual and reproductive health and rights. There is considerable linking between these two sections



# PLAN AND MANAGE

# A COMPREHENSIVE POSITIVE HEALTH, DIGNITY AND PREVENTION PROGRAMME OF ACTION

Step 1 of this guideline offered an example of how to assess and characterize the national landscape within the framework of Positive Health, Dignity and Prevention. Step 2 outlined ways to develop strategies to address individual components of Positive Health, Dignity and Prevention.

This section offers a suggested process on how to operationalise all of the components as one comprehensive and coherent programme of action. Eight action areas are recommended for the planning and management of a comprehensive and operational Positive Health, Dignity and Prevention programme of action based on Steps 1 and 2:

- 1 ADVOCACY AND POLICY DIALOGUE
- 2 PLANNING
- 3 IMPLEMENTATION
- **4 INTEGRATION**
- **5 COORDINATION**
- **6 CONTINUOUS EVIDENCE GATHERING**
- 7 MONITORING AND EVALUATION
- **8** ADAPTATION AND IMPROVEMENT

#### 1 ADVOCACY AND POLICY DIALOGUE

- Advocate for a Positive Health, Dignity and Prevention framework in the national, sectoral, organisational, and/or community response to HIV, and engage in a policy dialogue for effective change
- Mobilise political will and leadership for policy, legal, and programmatic reform with the leadership of PLHIV and networks of PLHIV
- Develop an advocacy and communications strategy that is specific to your organisation (internal), to your partners (external), or to your constituents (e.g., networks of PLHIV).

#### 2 PLANNING

Develop a long-term (3 to 5 years) and annual work plan for each of the components as well as for programmewide actions, with costed and SMART<sup>[15]</sup> activities, inputs, outputs, outcomes, objectives and goals. Include in your plan:

- A resource mobilisation and management strategy;
- An organisational management strategy;
- A partnerships development and coordination strategy;
- A logical M&E framework and mechanism for the process and impact;
- recommended adaptations and/or the development of new internal policies and guidance; and
- Staff development and support.

#### 3 IMPLEMENTATION

Implement the long-term and annual work plan in partnership with networks of PLHIV, civil society, and all relevant and appropriate stakeholders.

<sup>15</sup> Specific, measurable, attainable, realistic and time-bound

#### 4 INTEGRATION

In cooperation with partners, ensure that the Positive Health, Dignity and Prevention plan and programme of action is integrated into the broader work in the national response to HIV, which includes:

- National strategic plans;
- Resource mobilisation for HIV, development and economic empowerment;
- · Legal and policy reform;
- Health and communities systems strengthening; and,
- Mainstreaming HIV into sectoral work.

#### 5 COORDINATION

To ensure policy and programmatic action within the framework of Positive Health, Dignity and Prevention, coordination, constructive dialogue and information sharing between a diverse group of partners is needed. Partnerships should be fostered through inclusive, wellresourced coordination mechanisms. Existing coordination mechanisms, such as Country Coordinating Mechanisms or national AIDS councils, may need to be reviewed and strengthened, and civil society coordination bodies may have to be developed and supported.

#### 6 CONTINUOUS EVIDENCE GATHERING

Gather evidence on a continuous basis, at all phases of implementation – that is, during development, rollout, adaptation and improvement - with the meaningful involvement and leadership of PLHIV. As an example, the PLHIV Stigma Index may provide invaluable evidence on what actions need to be taken towards reducing stigma and discrimination. Re-implementing the PLHIV Stigma Index after those actions have taken place can support measurement of the effectiveness and impact of those actions.

#### 7 MONITORING AND EVALUATION

- Develop a set of indicators, which will be used to monitor and evaluate the impact and effectiveness of your plan.
- Ensure that monitoring and evaluation is an ongoing aspect of all your actions.
- Dedicate adequate resources (technical, human and financial) towards the operationalisation of an M&E framework and mechanism.

#### 8 ADAPTATION AND IMPROVEMENT

When applying the lessons learned and improving upon previous work, the following should be taken into consideration:

- Adapt and improve activities in long-term and annual work plans on a regular basis based on the lessons learned (see above on M&E and evidence gathering) as well as to incorporate emerging evidence and guidelines (e.g., on new guidance such as those for new programmatic guidelines on PMTCT, treatment as prevention, or the emergence and availability of a new prevention technology).
- Document the lessons learned and share these with partners at the national, regional and global levels.

Throughout all of the action areas above, an underlying principle is the meaningful and inclusive engagement of PLHIV and networks of PLHIV and organisations.

The Strategic Investment Framework<sup>[16]</sup> offers a model to optimise responses to HIV. The Positive Health, Dignity and Prevention framework results in better outcomes both for PLHIV and for communities as a whole: the Investment Framework model may support the planning, resourcing and implementation of Positive Health, Dignity and Prevention related programmes as well as embedding them in a resourced national HIV response that meets the needs of all communities.

<sup>16</sup> See UNAIDS. 2012. Investing for results. Results for People. A people-centred investment tool towards ending AIDS (http://www.unaids.org/en/media/unaids/ contentassets/documents/pcb/2012/JC2359\_investing-for-results\_en.pdf) and Bernhard Schwartländer et al., 2011. Towards an Improved investment approach for an effective response to HIV/ADS, The Lancet, Volume 377, Issue 9782, Pages 2031 - 2041, 11 June 2011.

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# SUGGESTED STEPS TO DEVELOP, IMPLEMENT AND MONITOR A POSITIVE HEALTH, DIGNITY AND PREVENTION PROGRAMME



# ASSESING WHERE YOU ARE: NATIONAL POLICY, LEGAL PROGRAMME ENVIRONMENT

Below are some suggested steps to follow in order to identify opportunities for enacting a Positive Health, Dignity and Prevention programme of action in your country or for your organisation.

#### SUGGESTED PROCESS:

## 1 Who are the people living with HIV in your country?

Putting people living with HIV in the centre requires understanding who is living with HIV. It is important to know characteristics of the populations of people living with HIV

- By gender and age
- Socio-economic demographics (e.g., employment status, ethnic identity, education levels, etc.)
- Where they live (e.g., ruralh or urban settings)
- If they are key populations living with HIV (e.g., MSM, sex workers, people who use drugs, women living with HIV, prisoners, etc.).
- All of these demographic characteristics will allow you to determine
- Whether and how individuals are able to access services,
- Whether and how literacy and education programmes reach individuals, and
- The strengths, gaps and limitations in terms of delivering a comprehensive and inclusive set of services to meet their needs.

Table 4 on page 52 provides an example of how to list populations of PLHIV. Quite often, evidence is lacking in terms of PLHIV prevalence by categories beyond gender and mode of transmission. Knowing where epidemiological evidence gaps exist is also an important step in determining how to overcome challenges and develop inclusive policies and programmes.

## 2 What evidence is available on the experiences and priority needs of PLHIV in your country?

Developing an evidence-informed strategy operationalising Positive Health, Dignity and Prevention needs to be based on evidence which pinpoints the

priority needs of PLHIV based on their experiences in accessing health, education and employment; living in their communities; and pursuing human rights. Evidence on the experiences of PLHIV may be found in research from academic institutions, national surveys, evaluation of programmes and services, or community-led action research.

Evidence on the experiences and priority needs of PLHIV may be analysed through different 'lenses', such as the following:

- Access to services for HIV treatment, prevention, care and support, including sexual and reproductive health. It is important to look for evidence not only on coverage levels of services, but also evidence on the quality of services that affect accessibility for PLHIV.
- Experienced stigma and discrimination. The PLHIV Stigma Index, for example, if implemented in your country by the national network of PLHIV, will provide evidence on where and how externally experienced stigma manifests itself within the community and how self-stigma affects the quality of life of PLHIV.
- Human rights violations. The Human Rights Count!, for example, where implemented by the national network of PLHIV, provides evidence on when and how human rights violations occurred as well as what redress actions were taken and the outcomes of such actions. Moreover, where redress was not possible, it provides evidence as to why.
- Quality of life of PLHIV. This includes evidence on the condition and experiences of PLHIV relative to the general population in terms of education, economic status, employment, etc.
- Key populations living with HIV. Most often, evidence on key populations living with HIV is limited to young people and women living with HIV. Evidence on MSM, sex workers, and people who use drugs living with HIV is often scarce or entirely absent. If available, however, it can provide invaluable insight into how to overcome challenges to ensuring the human and health rights of marginalised populations facing the overlapping vulnerabilities of marginalisation and HIV infection.

#### 3 How is the response to HIV in your country coordinated?

This step requires determining the main coordinating bodies in the country, including the lead agency, the partners, and which guidance resources are used. One way to categorise these could be:

- National HIV response level (e.g., National AIDS Council or Programme, Country Coordinating Mechanism, coordinating mechanisms between HIV and SRH; also includes regional and district level responses);
- Sectoral coordination (e.g., Ministry of Health, Ministry of Education, Labour and Employment, Social Support, etc.);
- Thematic, short-term / limited or long-term (e.g., Tribunal for Human Rights of PLHIV, Commission on Legal Reform of HIV-related travel, residence, and stay restrictions); and
- Stakeholder type (e.g., Parliamentarian groups, inter-faith working groups, civil society coordinating bodies on HIV, etc.)

In addition, it is important to consider this step in conjunction with the next. That is, issues surrounding coordination often overlap and are informed by a country's guiding strategy documents. Thus, when considering coordination, it is necessary to also consider the national policy and guidelines in place pertaining to Positive Health, Dignity and Prevention; the national strategy and framework related to HIV prevention; and any national treatment and care guidelines as well.

- > Table 1 on page 85 and table 2 on page 88 provide a possible categorisation to assist you in this step.
- 4 What are the main legal and policy frameworks that define how and where the response to HIV in your country is directed and delivered? For example:
- National strategic plans (long-term and annual work plans) and supporting guidance and policies related to HIV and SRH;
- Global Fund to Fight AIDS, Tuberculosis and Malaria grants and supporting guidance related to implementation and coordination (in countries where Global Fund grants have been awarded), PEPFAR requirements and structures (where applicable), and also local money available to and supporting the AIDS response; and
- Legal frameworks (PLHIV-specific; same-sex sexual relationships; access to health, employment and education rights; related to people who use drugs and access to harm reduction; travel, residence and stay restrictions based on HIV status; gender equality; SRHR; etc.).
  - > Table 3 on page 90 provides one possible method to assist you in this step.

#### 5 What are the social determinants of vulnerability to HIV?

Effectively responding to the needs of PLHIV requires understanding and addressing the social determinants of vulnerability to HIV beyond access to treatment, prevention, care and support services. For example:

- Social determinants experienced by the individual: stigma towards PLHIV and key populations; gender; attitudes related to sex, sexuality and drug use; the role of faith and culture; etc.
- Social determinants experienced by the community and/ or country as a whole: the broader economic situation and available resources for services; unemployment levels; literacy and educational opportunities; capacity of health, education and employment systems and sectors; and access to healthcare, social services, etc.

## Who are the main stakeholders responding to HIV in your country?

Some of the steps above involve mapping the primary stakeholders in the national response to HIV (and SRH) and identifying the relative role of each. One way to categorise them could be.

- Public sector and governmental bodies, including health service managers, providers and the broader health sector;
- Political parties and leaders;
- Donors and development agencies;
- National and international civil society organisations and faith-based organisations;
- Networks of PLHIV and key populations;
- Other networks (e.g., employee unions, teacher unions, etc.);
- Advocacy institutions;
- Media and information-sharing agencies;
- Research and academic institutions; and
- Other stakeholders.

## What resources are available to respond effectively to and meet the needs of PLHIV (human and financial resources)?

- Who provides the resources (e.g., Global Fund grant, international aid, national contribution, public donations, etc.)?;
- What areas of work do those resources support. including any areas of work which are NOT supported (advocacy, civil society, public awareness, procurement of equipment, training of service providers, public awareness raising, SRHR, legal reform actions, research, etc.)?;
- What are the relative gaps or strengths in resources available for treatment, prevention, care, support and SRH?

## 8 What are the roles of civil society and key populations?

Here, it is important to understand how civil society and key populations are involved in national-level responses to HIV. In particular, consider if there are any particular policies that enable or prohibit the participation and/or involvement of civil society organisations or networks. Specifically, consider:

- Participation in national coordination and the monitoring of the national response to HIV;
- Advocacy and ability to influence policy change;
- Programme and service delivery, and what programmes are those; and
- Supporting or facilitating access to education, employment, health and social protection services.

## What is the role of networks of PLHIV in the response to HIV?

Similar to the above step, this step involves assessing the level and quality of the meaningful engagement of PLHIV and networks of PLHIV. Here, you should specifically examine the level and quality of participation of networks and organisations of PLHIV in:

- Participation in national coordination and the monitoring of the national response to HIV;
- Advocacy and ability to influence policy change;
- Programme and service delivery; and
- Supporting or facilitating PLHIV access to education, employment, health and social protection services.

## 10 What is the role of your organization in the HIV response within the framework of Positive Health, Dignity and Prevention? Specifically assess your organisation's ability to reach PLHIV and address the following:

- Empowerment;
- Health access and promotion;
- Gender equality;
- Sexual and reproductive health and rights;
- Prevention of new infections:
- Human rights:
- Social and economic support; and
- Monitoring impact.

In turn, you will need to consider how your organisation determines its role in meeting the needs of PLHIV based on the list above. Specifically, think about how do you address these issues in the following:

- Long-term organisational strategic plan;
- Annual work plan; and
- Internal organisational policies (e.g., partnership strategies, workplace policies, professional development and training, etc.).

Taken as a whole, the above inventory of issues will allow you to know your epidemic at the country level and better understand where action is needed to realise the Positive Health, Dignity and Prevention framework.

# **ASSESS AND OPERATIONALISE HE COMPONENTS OF** POSITIVE HEALTH. DIGNITY AND PREVENTI

## EMPOWERMENT OF PLHIV AND NETWORKS OF PLHIV

#### MEANINGFUL INVOLVEMENT OF NETWORKS OF PLHIV

## 1 Map processes and mechanisms that provide opportunities of engagement

List the processes, mechanisms and coordination bodies (see page 16).

#### 2 Assess the current format of engagement

For each process and mechanism specific to your organisation or country or those most relevant, identify how networks of PLHIV are engaged. Consider if networks of PLHIV are involved as:

- Members of the governance body;
- Equal and active partners or as rubber stamps required to pass issues or decisions;
- Acting in an advisory capacity or on a regular or ad hoc basis;
- Observers;
- Those providing services that are developed by the coordination body;
- Recipients of information; and/or
- Recipients of funds.

## 3 Map out existing guidelines and documentation

Examine the following:

- Policies and guidelines that articulate the why and how organisations such as networks of PLHIV can be involved. These may include CCM guidelines (if your country is a Global Fund recipient), national strategic plans, operational guidelines of national AIDS councils, national AIDS policies (or the equivalent), etc.
- Membership guidelines or terms of reference for members of the coordination body or process.
- State, organisational or ministerial policies and regulations on the participation of civil society in public sector work.

## Identify and assess successes and challenges

There are many factors that influence the level and quality of participation of networks of PLHIV. Some are internal to the networks, some are the internal practice and policy of the coordinating body or government, and some are based on the attitudinal and cultural factors of the broader community.

For example, consider the list below - either in terms of existence or absence - and if they represent successes or barriers to the meaningful engagement of networks of PLHIV:

- Political will, leadership and support in the country or your organisation regarding PLHIV engagement and the role in the response to HIV.
- Network's capacity and resources that may allow participation in meetings as well as carrying out tasks assigned to members of the coordination body.
- Legal frameworks that enable or create barriers to engagement. These may be related to networks of PLHIV specifically, or more broadly to civil society engagement in national policy and programming. They may even be related to the ability of networks of key population to form and to engage as partners.
- Levels of stigma and discrimination within the community or within the coordination body.

## Look for evidence related the level as well as quality of involvement

Consider the following:

- Global AIDS Response Progress Reports from your government as well as civil society shadow reports.
- GIPA Report Card from your country or other countries in the region (see the GNP+ website for a complete list).
- Reports to Global Fund from your country.
- Reports from CCMs, national AIDS councils, Ministry of Health AIDS coordination bodies, etc.

## 6 Take follow-up steps to improve the level and quality of engagement of networks of PLHIV

- Advocate with your colleagues and members of the coordination body regarding why the participation of networks of PLHIV is important and the likely outcomes.
- Mobilise political and organisational leadership.
- Involve the network of PLHIV throughout the follow-up steps to ensure its meaningful involvement and alignment with the network's priorities and capacity needs and strengths.
- Review membership of partners and coordination and determine opportunities for engagement of the network of PLHIV.
- Adapt current policies and remove legal barriers to the engagement of civil society and the network of PLHIV.
- Adapt current guidelines and terms of reference to provide guidance on how partners engage meaningfully and equally.
- Address stigmatising attitudes within organisations and coordination bodies.
- Determine resources required to allow for network participation.
- Monitor progress related to the engagement of all partners including the network of PLHIV in order to respond to gaps and challenges timely and efficiently.

#### MEANINGFUL INVOLVEMENT OF PLHIV

## Map services, programmes and processes that provide opportunities of engagement

List the types of programmes and/or services delivered 4 by your organisation that are most relevant to PLHIV – i.e., those programmes that are directly aimed at people living with HIV (e.g., testing and counselling, PMTCT, treatment access and adherence, monitoring of human rights violations, programmes to develop guidelines for SRHR of PLHIV, home-based care services, etc.).

Identify other opportunities for raising social capital mobilising people living with HIV - perhaps on specific occasions (e.g., World AIDS Day) or for a particular programme (e.g., PLHIV Stigma Index).

List the programmes or services that are directed at others in order to improve the quality of life of those living with HIV (e.g., programmes on workplace policies to reduce stigma as well as to improve the working conditions for PLHIV, healthcare worker training guideline development, HIV-related stigma reduction programmes, etc.).

List the programmes or services that can reduce vulnerability to HIV and could benefit from the experiences of those living with HIV (e.g., prevention awareness

campaigns, sex and sexuality education, development of guidelines for health care provision, development of guidelines for home-based care givers etc.).

### 2 Assess the current format of engagement

For the programmes, services or processes you listed that are most relevant to your organisation or country, identify how PLHIV engaged. For example, determine if PLHIV are

- Members of the governance/coordination body;
- Paid staff:
- Volunteers:
- Peer supporters:
- Providing the services your organisation delivers;
- Those accessing the services or programmes you offer;
- Trainers or participants or beneficiaries of trainings;
- Recipients of information; and/or
- Providers of information on a regular or ad hoc basis.

## Map existing guidelines and documentation and evidence on the engagement of PLHIV thus far

Here, attention should be directed toward the following:

- Policies and guidelines that articulate why and how people living with HIV (or patients in general) or community members are engaged in programmes designed for them.
- Reports from programme evaluations that provide details regarding the impact of engagement of PLHIV and how to improve the level and quality.

#### Assess the success and challenge factors

Factors that influence the level and quality of participation of PLHIV may include the internal policies of your organisation, the human and financial resources available, the capacity and available resources of the local network of PLHIV, and broader societal attitudes and cultural factors. It is useful to identify the presence or absence of the following factors or barriers to the meaningful engagement of PLHIV:

- Political and organisational will, leadership and support.
- Resources available to meaningfully engage PLHIV.
- Resources available for skills and professional development.
- Legal and policy frameworks that enable or create barriers to engagement. These may be related to issues pertaining to sex work, drug use, sexual orientation, or gender equality.
- Levels of stigma and discrimination within the community or the organisation regarding people living with HIV and/or key populations.

### Take follow-up steps to improve the level and quality of involvement of PLHIV

- Advocate amongst your colleagues why the participation of PLHIV is important and the potential outcomes
- Reach out to the local network of people living with HIV. The network can support you to develop appropriate and effective methodologies of engagement which will be representative as well as protective of those engaged from further stigma or discrimination. This assumes that the local network of PLHIV Is a relevant political stakeholder and is active in the local-level responses.
- Determine priority areas and programmes for which the level and quality of engagement of PLHIV must be increased or revised.
- Mobilise political and organisational leadership.
- Adapt current policies and guidelines to ensure that it is possible to engage PLHIV and that their engagement is meaningful, supported, monitored and evaluated. Also, ensure that guidelines are shared not only among PLHIV, but also among everyone involved.
- Address stigmatising attitudes within the organisation and among service providers.
- Review organisational management to identify opportunities for the greater involvement of PLHIV as well as to support PLHIV who may be working within the organisation.
- Determine resources required to allow for the participation of PLHIV.
- Monitor engagement and share good policy and practice.

#### PLHIV LEADERSHIP DEVELOPMENT

- Map services, programmes and processes that provide opportunities for leadership development and renewal of PLHIV (mostly for individuals, but also including when people living with HIV are collectively mobilised - e.g., social capital related mobilisation)
- 2 Map other services, programmes and services for leadership development and renewal

These may include leadership development programmes designed for key populations, for civil society leadership, for community leadership, etc.

#### 3 Map opportunities for capacity strengthening in technical thematic areas

These may include on-going or one-time seminars on technical areas such as the introduction of new guidelines on treatment, on gender equality, on M&E, etc.

## 4 Assess lessons learned, opportunities, successes and challenges

- Identify the lessons learned from evaluations of leadership development or training programmes
- Identify the specific challenges, opportunities and successes related to leadership development
- Identify the available resources (i.e., human, financial, partners') which may support leadership programmes

## Take follow-up steps to improve the leadership development and renewal of PLHIV

- Advocate amongst your colleagues, explaining why leadership development for PLHIV is important and why such programmes are an effective use of resources
- Engage current leadership among PLHIV and learn from them about their experiences
- Engage the local network of people living with HIV to support you to develop appropriate and effective methodologies for leadership development programmes
- Mobilise organisational support and create opportunities for training and skills development for PLHIV, in particular within your organisation
- Review organisational management to allow for PLHIV leadership development
- Determine the resources required
- Monitor the impact and success and support PLHIV in terms of accountability and responsibility

#### CAPACITY STRENGTHENING OF NETWORKS OF PLHIV

- Map areas of support your or other organisations provide to strengthen the capacity of networks of **PLHIV** (see table for areas where support is needed)
- 2 Assess your organisation's ability to provide or past experience in providing support
- Identify your organisation's policy allow for core funding support and on advocacy skills development
- Identify any restrictions which exist in your policies
- Identify reporting requirements
- Identify organisational criteria necessary for a network to access support
- Identify type of support your organisation has provided thus far and with what outcomes

## 3 Collaborate with networks of PLHIV to assess current gaps and strengths in support

- Identify priority areas of capacity strengthening. including how they compare with the levels of support currently available for each area
- Identify all networks of PLHIV in the country and the levels of support they experience

#### 4 Assess opportunities and bottlenecks

- Identify possible sources of support
- Identify key partners involved in support mobilisation
- Identify main challenges that need to be overcome so that support may be provided, including any which are network-specific, and which are donor-specific
- Identify the thematic areas of support which are and are not possible

## 5 Follow-up steps to improve and strengthen the capacity of networks of PLHIV

- Advocate amongst your colleagues regarding why strengthening the capacity of networks of PLHIV is essential to effective national responses to HIV and mobilise political and organisational leadership
- Adapt current policies which may be barriers to accessing support by the networks of PLHIV, in particular, for core funding and advocacy
- Remove legal barriers which may not allow for civil society participation in national processes or which may not allow civil society work designed to respond to the needs of key populations
- Mobilise resources and support for networks of PLHIV in thematic areas which they have identified as priorities
- Provide guidance on reporting procedures by the network of PLHIV on any support received through this work
- Monitor and evaluate the outcomes and impact of support and share lessons learned

## PLHIV LEGAL, RIGHTS AND HEALTH LITERACY

Legal, rights and health literacy of PLHIV represent a common thread running through all components of Positive Health, Dignity and Prevention. Therefore, please review other components before proceeding with the steps listed below.

## 1 Collaborate with a network of PLHIV to assess the level and source of legal, rights and health literacy of PLHIV

Existing or past programmes by the network may have resulted in evidence to support assessment. In some cases, evidence gathering may be necessary.

- Determine how PLHIV receive legal, rights and health literacy through treatment programmes, legal services. etc. In other words, identify the lessons learned specifically with regards to literacy from reviewing other components of Positive Health, Dignity and Prevention.
- Determine which organisations have been providing legal, rights or health literacy for PLHIV and with what outcomes.
- Determine the sources of knowledge (e.g., peers and support groups, schools, media, health facilities, civil society distributed informational materials, etc.).

## 2 Assess the level and source of literacy on legal, rights and health for the general population

For example, identify the availability and breadth of sex and sexuality education programmes in schools, public awareness programmes by the Ministries of Health or Labour, etc.

## 3 Assess the lessons learned, opportunities, challenges and successes

- Identify priority areas for improving levels of awareness among PLHIV
- Identify any specific sub-populations of PLHIV who may require more support than others
- Identify impact of literacy programmes

## Follow-up steps to improve legal, rights and health literacy of PLHIV

- Gather evidence on how PLHIV access and their level of knowledge related to their rights, how to access and manage treatment, and how to manage their health
- Review and revise legal rights and health literacy elements of components on health access and promotion, human rights, SRHR, gender equality, prevention of new infections and social and economic support
- Meaningfully involve the network of people living with HIV at all stages of programme development, design, planning, implementation, monitoring and evaluation
- Ensure that information targeted to PLHIV is accurate, age- and gender-appropriate, evidenceinformed, and culturally appropriate
- Sensitise and train those who deliver information such as media, educators, service providers, religious leaders and other relevant stakeholders
- Provide support for PLHIV to develop skills and be peer educators
- Adapt current policies and laws which may create challenges in empowering PLHIV to receive information and inculcate that information into knowledge
- Monitor the impact of literacy programmes

## **HEALTH PROMOTION AND ACCESS**

MAP PROGRAMMES AND SERVICES

**INFECTIONS AND ILLNESSES** 

**QUALITY ASSURANCE** AND IMPROVEMENT

	TREATMENT ACCESS	Testing and counselling programmes (voluntary or provider initiated, linked with reproductive health services, provided on a regular or irregular basis, types of testing (antibody, rapid test, etc.))  Clinical monitoring and diagnostics (when and how CD4 count is available, viral load, other blood indicators and health diagnostics)  Adherence support to PLHIV on ART  - By whom: support groups, health providers, through informational material, etc.  - On what: management of side effects, for parents of children living with HIV, etc.  Treatment literacy  - By whom: health care providers, community organisations, support groups, etc.  - What format: informational material, training, public awareness, etc
	CARE AND SUPPORT	<ul> <li>Palliative care (what type of care, and who provides it)</li> <li>Psychosocial, mental and emotional health services (stand alone or integrated into counselling, type of support, who provides it, etc.)</li> <li>Counselling services and support groups</li> <li>Facilitated referral systems</li> <li>Social protection (see also Social Protection component)</li> <li>Family planning and support (see also SRHR component)</li> </ul>
	PREVENTION, DIAGNOSIS AND TREATMENT OF OTHER INFECTIONS AND ILLNESSES	<ul> <li>TB prevention and treatment</li> <li>Treatment and prevention of opportunistic infections</li> <li>Diagnosis and treatment of Hepatitis C and other co-infections</li> <li>Treatment and prevention of non-communicable diseases (cancer, cardiovascular illnesses, etc.)</li> <li>OST for people who use drugs living with HIV</li> <li>STI diagnosis and treatment (see also SRHR component)</li> <li>Treatment of ART side effects (e.g., heart diseases due to ART)</li> <li>Prevention of disease progression and further infections</li> <li>Literacy on health and healthy living with HIV</li> </ul>
	QUALITY ASSURANCE AND IMPROVEMENT	<ul> <li>ARVs (specific drugs available, since when available, prescribed combinations, institutions providing them to PLHIV, age-specific dosage availability, eligibility criteria for initiating ART, etc.)</li> <li>Support to and skills building of health care providers ('type of support' and the 'recipient'. For example, who receives training on clinical protocols and guidelines, what type of support is given to whom in terms of developing counselling and adherence skills, etc.)</li> <li>Monitoring, improvement and ensuring quality of services</li> </ul>
2	EVIDENCE: MAP OUT	COVERAGE AND DETERMINE GAPS
	TREATMENT ACCESS	
	CARE AND SUPPORT	Determine existing gaps in coverage by mapping the current level of coverage by gender, age group, area of residence, socio-economic status, and key population. This will allow you to
	PREVENTION, DIAGNOSIS AND TREATMENT OF OTHER	determine gaps in access and provide insights as to how to overcome access barriers. It may become apparent that evidence on 'coverage' is absent or limited. Identifying where evidence

gaps exist is itself an important step in overcoming barriers to access

geographical location, etc

Determine coverage of support provided to health care providers by type of health care

institution, position level in the health care system or service, by level of education, by

## **EVIDENCE: COSTS AND RESOURCES AVAILABLE**

#### TREATMENT ACCESS

#### Costs to PLHIV:

#### CARE AND SUPPORT

**INFECTIONS AND** 

**ILLNESSES** 

PREVENTION. **DIAGNOSIS AND** TREATMENT OF OTHER

**OUALITY ASSURANCE** 

AND IMPROVEMENT

including, for example, direct costs (health insurance, costs of ARVs to patient, costs for clinical monitoring and diagnostics, etc.); indirect costs (travel costs to and from health care centres, care for children, etc.)

#### Costs to and resources available for provider:

For some of the above (e.g., support groups and treatment literacy), community-led programmes may contribute in a way that may not allow for determining an actual cost.

## Costs to and resources available to the system:

including, for example, procurement of ARVs; stocking, monitoring and delivery systems; quality assurance and improvement and M&E; training of health care providers, coordination costs and resources, etc.

## MAP AND ASSESS EXISTING GUIDELINES

TREATMENT ACCESS Identify your country's guidelines and how they compare with the latest WHO guidelines: - On ART for adults and children, on testing and counselling, on clinical monitoring, on adherence, etc. Identify specific guidelines for PLHIV, including any guidelines for the general population on **CARE AND SUPPORT** care and support that are then applied for PLHIV PREVENTION. Identify your country's guidelines and how they compare with the latest WHO guidelines **DIAGNOSIS AND** - On the diagnosis and treatment of TB, Hepatitis C, and other co-infections (and specifically for TREATMENT OF OTHER PLHIV) INFECTIONS AND - Guidelines on the management of HIV infection and opportunistic infections **ILLNESSES** - Programmes for the training of health care providers **QUALITY ASSURANCE** - Guidelines for procuring, storing and distributing treatment AND IMPROVEMENT

#### **OTHER EVIDENCE** 5

## TREATMENT ACCESS

## **CARE AND SUPPORT**

PREVENTION. **DIAGNOSIS AND** TREATMENT OF OTHER **INFECTIONS AND ILLNESSES** 

- Country epidemiological reports
- Reports on the challenges or inability of PLHIV, in particular, key populations living with HIV, to access treatment, care and support
- Reports or evaluations from existing programmes

#### **QUALITY ASSURANCE** AND IMPROVEMENT

## 6 ASSESS THE SUCCESS AND CHALLENGES

#### TREATMENT ACCESS

#### **CARE AND SUPPORT**

PREVENTION, DIAGNOSIS AND TREATMENT OF OTHER INFECTIONS AND ILLNESSES

## QUALITY ASSURANCE AND IMPROVEMENT

The factors that affect the success of programmes and existing challenges will include a combination of the following:

#### **Systemic factors**

- Resources and capacity of system to deliver services, including the primary sources of financing and the ability of the national system to sustain financing
- Public health policy towards services and their delivery
- Political will and leadership
- Civil society and other partners' capacity
- Etc.

#### Policy and legal environment

(i.e., the parameters within which the system operates)

- Laws related to OST access
- Existence / absence of guidelines
- Etc.

#### Broader social drivers

- Stigmatising attitudes
- Socio-economic status of PLHIV
- Cultural and religious factors
- Etc

## 7 FOLLOW UP STEPS

#### TREATMENT ACCESS

#### CARE AND SUPPORT

PREVENTION, DIAGNOSIS AND TREATMENT OF OTHER INFECTIONS AND ILLNESSES

# QUALITY ASSURANCE AND IMPROVEMENT

- Share your work to date with partners and networks of PLHIV and initiate a dialogue on how to develop a time-bound action plan to improve the level and quality of health access and promotion for PLHIV
- Advocate with your colleagues regarding why the participation of PLHIV is important and the potential outcomes
- Meaningfully involve PLHIV and networks of PLHIV at all geographic levels and stages of design and implementation
- Integrate the comprehensive health access and promotion for PLHIV package into the national strategic plan and other national-level strategies, including health system strengthening
- Mobilise political and organisational leadership, with particular focus on areas where change is needed
- Demonstrate the impact of health access and promotion for PLHIV on broader health, development and social growth issues. In particular, identify how they relate to achieving the Millennium Development Goals and universal access
- Adapt current policies and remove legal barriers that may impede access to services for some populations and the meaningful engagement of PLHIV in the delivery of health promotion and access
- Address stigmatising attitudes in society and among those who provide services
- Address gaps in coverage in particular for key populations living with HIV and other underserved populations
- Review organisational and coordination management through linking health promotion and access for PLHIV into broader health and community systems strengthening through multisectoral responses and coordination
- Determine resources that will be required for scale up or addressing gaps, in particular for access to treatment
- Monitor and evaluate programmes on a regular basis and adapt programmes when and where necessary in a timely manner

## **GENDER EQUALITY**

## 1 Map areas where gender inequality may be challenging for PLHIV

- In terms of education, employment, social security and protection
- In terms of the accessibility and quality of services such as family planning, other SRH services, HIV treatment and prevention, etc.
- In terms of laws and policies that articulate the protection for equal rights or a divergence of rights based on gender (e.g., on inheritance, education, employment, access to services, etc.)
- In terms of cultural practices, social stigma and discrimination, social and religious gatherings, etc.

## 2 Review evidence of cases and the impact of rights violations and discrimination based on the gender of PLHIV.

For example, these may include the following:

- If the PLHIV Stigma Index has been implemented in your country, identify the different levels and types of stigma experienced by gender (female, male, transgender, MSM, sex workers, etc.).
- Identify any cases of forced sterilisation of women living with HIV, of gender-based violence, of women living with HIV who have faced violations of their rights such as inheritance or loss of housing or employment, etc.

## 3 Assess laws, policies, social and cultural practices that relate to gender equality

- These may be PLHIV-specific, such as criminal codes on HIV non-disclosure, transmission and exposure, and may also enhance the vulnerability of women living with HIV and key populations such as MSM.
- These may include general population laws and policies, such as on same-sex sexual relationships, access to education and employment, inheritance, social security and services and benefits.
- Cultural practices that may differ from legal and national policy guidelines.
- For each of the above, identify how these are enforced and practiced.

## 4 Map existing evidence and work identified for the reform and improvement of gender equality, in particular for those elements articulated for PLHIV in the table above.

- Describe how these efforts are integrated into general gender-equality efforts or are specific to PLHIV.
- Describe those areas of work on gender-

- equality for PLHIV and if any of these efforts have been evaluated or documented.
- Determine if there is any evidence on genderrelated violations of rights, such as the denial of services, forced sterilisations, etc.

## 5 Assess the successes and challenges related to effective and rights-based reform.

This may include:

- Political, organisational, religious, or community leadership positions
- Ability of civil society and networks to form and participate (in particular, women and key populations)
- Resources for adapting and reforming laws, policies and programmes for gender equality
- Societal levels of stigma and attitudes
- Level of engagement of men in gender equality
- Ability to work with civil society groups dedicated to gender equality

#### Take follow-up steps to improve gender equality of **PLHIV**

- Advocate for reform to achieve gender equality and mobilise political, organisational and community leadership, in particular, as gender-equality requires addressing change in the culture of work and practice.
- Engage and involve the local network of women living with HIV and networks of key populations, in particular, MSM and transgender people. These networks can support you to identify priority areas of work and develop appropriate and effective responses.
- Review organisational management and develop opportunities for the engagement of women living with HIV, MSM and transgender people in the response to HIV and gender equality.
- Gather evidence on the impact of gender inequality in the lives of PLHIV and their access to non-judgemental and rights-based health, education, employment and social protections.
- Adapt current policies, remove legal barriers and enact protective laws and policies.
- Operationalise protection services to address cases of rights violations within society as well as within organisations and service delivery.
- Address stigmatising attitudes and discriminatory practices within organisations and society.
- Monitor progress and re-evaluate responses designed to achieve gender equality on a regular basis and respond to emerging cases in a timely manner.

## **HUMAN RIGHTS**

1 MAD CURRENT I	AMIC POLICIES AND BROCK AMMES
LEGAL AND POLICY	AWS, POLICIES AND PROGRAMMES  Identify policies or laws currently in place on the issues listed below, indicating what the law/ policy states, and if it has ever been used to persecute or protect individuals
	Criminalisation, punitive and restrictive laws: - Transmission of and exposure to HIV - Travel, residence and stay restrictions based on HIV status - Same-sex relationships, sex work and people who use drugs (in particular, as it relates to access to OST)
	Protective Laws Confidentiality and disclosure of one's HIV status Family planning for PLHIV (in particular, access to PMTCT and the elimination of forced sterilisations) The rights of PLHIV related to access to treatment, health services, employment, education, etc
SYSTEMS FOR RIGHTS AND LAW ENFORCEMENT	<ul> <li>Monitoring systems for rights violations (e.g., related to health, employment, assaults, etc.)</li> <li>Redress and grievance mechanisms</li> <li>Legal services systems</li> <li>Legal enforcement systems</li> <li>Referral systems</li> </ul>
PROGRAMMES FOI PLHIV	<ul> <li>Legal services for women living with HIV who face gender-based violence and forced sterilisations</li> <li>Social services for PLHIV</li> <li>Training and sensitisation for service providers and law enforcement authorities</li> <li>Rights and legal literacy of PLHIV</li> <li>Self-stigma programmes</li> </ul>
PROGRAMMES FOI SOCIAL CHANGE	<ul> <li>Reduction and elimination of stigma and discrimination among the general population towards PLHIV and/or key populations</li> <li>HIV-related education for the general public</li> <li>Enforcement of equal rights to health, in the workplace, access to education, faith, communities, etc.</li> </ul>

2	MAP CURRENT LAWS	, POLICIES AND PROGRAMMES
	LEGAL AND POLICY REFORM	<ul> <li>Identify actions taking place now in terms of reviewing and/or revising laws and policies on the issues listed above</li> <li>Identify actions towards reviewing, revising, repealing, or enacting laws</li> <li>Identify actions related to translating law into policy and action</li> <li>Etc.</li> </ul>
	SYSTEMS FOR RIGHTS AND LAW ENFORCEMENT	<ul> <li>Identify actions currently taking place in terms of:</li> <li>Developing new systems</li> <li>Reviewing existing systems</li> <li>Strengthening capacity and skills</li> </ul>
	PROGRAMMES FOR PLHIV	- Identify types of programmes currently in place for the items listed above
	PROGRAMMES FOR SOCIAL CHANGE	- Indicate the lead agency and partners involved for each

3	MAP STAKEHOLDERS AND PARTNERS	
	LEGAL AND POLICY REFORM	<ul> <li>Identify the main stakeholders and partners involved in current work related to the revision, reform or enforcement of laws or policies</li> <li>Identify the positions relating to the particular law or policy</li> <li>Describe the position and role of PLHIV and networks of PLHIV in these areas</li> </ul>
	SYSTEMS FOR RIGHTS AND LAW ENFORCEMENT	- Identify the lead agency for work in these areas, as well as the supporting partners, and the
	PROGRAMMES FOR PLHIV	role of PLHIV or networks of PLHIV in the design, implementation and monitoring of these programmes
	PROGRAMMES FOR SOCIAL CHANGE	

4	EVIDENCE	
	LEGAL AND POLICY REFORM	<ul> <li>Identify available evidence in your country regarding the impact or use of these laws and policies</li> <li>Describe how these laws and policies have affected the rights of PLHIV and the level of treatment, prevention, care and support access</li> </ul>
	SYSTEMS FOR RIGHTS AND LAW ENFORCEMENT	<ul> <li>Identify available evidence in your country regarding how such systems have worked in the past</li> <li>Describe how PLHIV have accessed these services and systems with what outcomes</li> <li>If appropriate describe why PLHIV have not accessed such services</li> </ul>
	PROGRAMMES FOR PLHIV	- Identify available evidence on the success or impact of programmes in these areas
	PROGRAMMES FOR SOCIAL CHANGE	- Identify which programmes have been evaluated

5	CHALLENGES TO AND	OPPORTUNITIES FOR POSITIVE CHANGE
	LEGAL AND POLICY REFORM	<ul> <li>List the gaps, challenges to and opportunities for positive change:</li> <li>Political will and leadership</li> <li>Religion and culture</li> <li>Capacity and resources</li> <li>Existence or absence of evidence related to the impact and evaluation of programmes</li> <li>Existence or absence of guidelines or examples of good practice</li> <li>Capacity and/or level of the meaningful involvement of PLHIV and networks of PLHIV</li> </ul>
	SYSTEMS FOR RIGHTS AND LAW ENFORCEMENT	
	PROGRAMMES FOR PLHIV	
	PROGRAMMES FOR SOCIAL CHANGE	



#### **FOLLOW-UP STEPS**

#### LEGAL AND POLICY **REFORM**

SYSTEMS FOR **RIGHTS AND LAW ENFORCEMENT** 

#### PROGRAMMES FOR **PLHIV**

#### PROGRAMMES FOR **SOCIAL CHANGE**

- Share your findings with partners including networks of PLHIV and initiate a dialogue on how to develop a collaborative, evidence-informed, time-bound action plan to overcome challenges and improve the human rights of PLHIV
- Determine and/or mobilise the resources you will need to put into place the action plan
- Advocate amongst your colleagues why addressing the human rights of PLHIV represents an effective way of responding to HIV
- Advocate at national level to address gaps or restrictive laws and policies
- Mobilise political and organisational leadership for changes in the 'culture of work', the allocation of resources, and leading the move to change by example
- Adapt and reform current policies and laws that may create systemic barriers to positive change, enact protective laws and policies where there are none or where the human rights of PLHIV have been violated, and repeal laws that violate the human rights of PLHIV
- Remove legal barriers that impede access to treatment, prevention, care and support for PLHIV
- Reach out to others who have been engaged in addressing the human rights violations of PLHIV and share lessons learned
- Address stigmatising attitudes and discriminatory practices both within organisations and within communities. This may mean challenging cultural norms, encouraging dialogue among diverse sets of stakeholders, and empowering those most marginalised and vulnerable to lead the response to change
- Document cases and the impact of human rights violations and respond to violations by taking actions to protect and restore the rights for victims
- Review the organisational management to ensure that the human resources and skills necessary to protect the human rights of PLHIV are in place
- Monitor progress and evaluate the success of any programmes your organisation puts into place

## PREVENTION OF NEW INFECTIONS

## 1 Assess priority areas of prevention for PLHIV with their meaningful engagement to ensure that priorities are determined by and for PLHIV

Within the contexts of gender inequality, stigmatising attitudes and laws (e.g., on the criminalisation of nondisclosure, transmission and exposure, same-sex relationships, sex work, people who use drugs, etc.), and discriminatory practices, identify the priority areas of 3 improvement and scale-up.

#### For example:

#### For the prevention of sexual transmission

- Condoms: availability, accessibility and affordability; negotiation skills for use with one's sexual partner; risk assessment
- Support for sero-discordant couples: couples' counselling and prevention literacy; PreP for MSM sero-discordant couples; family planning services
- ART for prevention
- Education and prevention literacy (for PLHIV specifically or in general, e.g., in schools and public education programmes).

## For the prevention of injecting drug use- and other substance use-related transmission

- Access to clean needles, OST, psychosocial support, education, negotiation skills for not sharing injecting equipment
- Access to harm reduction strategies to substance use (including alcohol and drugs)

#### For the prevention of vertical transmission

Family planning, other sexual and reproductive health and rights (SRHR) services, prevention of mother-to-child transmission (PMTCT) access integrated into life-long treatment access for parents living with HIV, integration of PMTCT with paediatric health services, education and prevention literacy for women and men living with HIV

## 2 Assess the level and quality of programmes delivering prevention for PLHIV

- For each of the areas identified, and specifically for the priority areas articulated by the assessment in the step above, identify the current levels of achievement in coverage as well as towards ensuring quality
- Describe how the priorities differ for women, men, young people, MSM, transgender people, people who use drugs, sex workers, and other key populations living with HIV

- Identify any variances that exist with regards to the location of residence, cultural practices, or faith communities, etc.
- Describe the lessons learned in comparing the current level and quality of prevention programmes for PLHIV with the priority areas identified in collaboration with PLHIV, including any variances or overlaps
- Map and analyse the national policies and guidelines related to access to prevention in steps 1 and 2 above.

## 4 Assess how 'shared responsibility' for prevention and transmission is developed

This should include assessments of the following:

- Prevention education and public HIV awareness campaigns
- Absence or presence of laws criminalising HIV non-disclosure, transmission or exposure
- Media and public messages
- Other

## Assess successes achieved and challenges faced by PLHIV in accessing prevention, such as:

- Those related to legislation and policy
- The availability, accessibility and quality of delivery of prevention commodities and services
- Knowledge and prevention literacy
- Social, economic or cultural factors

## Identify available evidence on the level and quality of the involvement of people living with HIV in prevention programmes

- For prevention programmes targeted to PLHIV
- For prevention programmes targeted to the general public

## Take follow-up steps to improve the level and quality of the prevention of new infections

- Advocate amongst your colleagues regarding the justification for the shift from the traditional 'positive prevention' to 'Positive Health, Dignity and Prevention' approach to the prevention of HIV transmission by and for PLHIV, which is essential to an effective response to HIV
- Reach out to and engage the local network of people living with HIV to develop appropriate and effective methodologies that are appropriate for PLHIV

- Mobilise political and organisational leadership
- Remove legal barriers to accessing effective and comprehensive prevention
- Adapt current policies and programmes
- Integrate prevention into SRHR, (including family planning, maternal health, sexually transmitted infection prevention and treatment, gender-based violence prevention and management), harm reduction, education, and health access programmes appropriate for PLHIV)
- Train and sensitise service providers
- Involve PLHIV at all stages of the review, design, implementation, monitoring and evaluation of existing laws, policies and programmes
- Address stigmatising attitudes and discriminatory practices amongst service providers and within communities
- Monitor both the level and quality of prevention programmes

## SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS

## Assess priority areas of SRHR for PLHIV through their meaningful engagement to ensure that priorities are determined by and for PLHIV

Here, it is important to identify the priority areas of improvement and scale-up within the contexts of gender inequality, stigmatising attitudes and laws (e.g., on the criminalisation of HIV transmission and exposure, samesex relationships, sex work, family planning options, etc.), cultural contexts, and religious beliefs. This may include:

#### Sexual health and well-being

- Education on and access to the diagnosis and treatment of sexually transmitted infections
- Education, counselling and support
- Services responsive to key populations (e.g., for young people, women, MSM, sex workers, prisoners, and transgender people living with HIV)

#### Reproductive health

- Maternal health
- Access to other reproductive health services (such as cancer screenings and treatment)
- Family planning, including pregnancy termination services
- Addressing coerced or forced sterilisations
- Access to PMTCT
- Sex and sexuality counselling
- Couples counselling and support

#### Sex and sexuality

- Comprehensive sex and sexuality education
- Age- and gender-specific sex and sexuality support

#### Human rights

- Right to the partner of one's choice (or decide not to have a partner, to have several, etc.)
- Right to choose when and how many children to have
- Removing legal barriers (including criminalisation laws on HIV transmission and exposure, punitive laws on same sex-sex relationships, sex work, etc.)
- Addressing rights violations, and stigma and discrimination in communities and in the provision of services

## Assess the level and quality of programmes delivering prevention services for PLHIV

- For each of the areas identified, and, in particular, those priority areas articulated by the assessment in the step above, describe the current levels of achievement in coverage as well as in ensuring quality
- Identify how priorities differ for women, men, MSM, transgender people, people who use drugs, sex workers, prisoners, young people, and other key populations living with HIV
- Describe existing variances depending on the demographic characteristics of PLHIV
- Identify the lessons learned in comparing the current level and quality of SRHR for PLHIV with the priority areas identified in collaboration with PLHIV, including any variances and overlaps
- Identify existing evidence available that describes the current experiences of PLHIV in SRHRrelated issues (e.g., PLHIV-driven evidence, Human Rights Count!, PLHIV Stigma Index)

- Map and analyse national policies and guidelines related to the SRHR of PLHIV in steps 1 and 2 above
- 4 Assess the successes and challenges affecting the SRHR of PLHIV, such as:
- Related legislation and policy
- The availability, accessibility and quality of education and service delivery which is non-judgemental and rights-based
- Education and literacy of PLHIV on SRHR
- Social, economic or cultural factors
- 5 Assess the level of integration of SRHR services in HIV-related programmes and vice versa

Please note: Integration may not always be possible or appropriate. However, this assessment may provide insight into the entry points for meeting the SRHR needs of PLHIV as well as where the quality and level is not appropriate.

- 6 Take follow-up steps to improve level and quality of SRHR
- Advocate amongst your colleagues why meeting the SRHR needs of PLHIV is an

- effective response to HIV and an effective response to addressing human rights
- Reach out to and engage the local network of people living with HIV, women living with HIV, and key populations to develop appropriate and effective methodologies that are appropriate for PLHIV
- Mobilise political, organisational and community leadership; community leadership is particularly important in affecting a change in the culture of work and practice in relation to SRHR of PLHIV
- Remove legal and adapt current policies and programmes
- Review programmes and guidelines to ensure that they are age-specific, gender-responsive, culturally appropriate and evidence-informed
- As much as possible or needed, integrate SRHR and HIV-related programmes
- Train and sensitise service providers
- Involve PLHIV at all stages of the review. design, implementation, monitoring and evaluation of laws, polices and programmes
- Address stigmatising attitudes and discriminatory practices from service providers and within communities
- Monitor both the level and quality of programmes

## SOCIAL AND ECONOMIC SUPPORT

- 1 Map existing social and economic support This may include the following:
- Access to education, employment, social security, and health insurance schemes
- Programmes for micro-financing and creating employment opportunities
- Social services such as childcare, housing, unemployment benefits, cash transfers, etc.
- The integration of migrants, the rehabilitation of previously incarcerated persons, etc.
- Literacy and empowerment programmes for women and young people

Map how social and economic support is currently accessed by PLHIV

This includes:

- Identify the process by which PLHIV access programmes - through programmes specifically designed for PLHIV or through general population programmes which PLHIV also access
- Identify available referral systems through treatment, care and support services
- Describe level of public awareness and availability of education on rights and social care
- Determine education, employment, and health care entry points
- Determine what is a available to PLHIV through community support systems

## 3 Determine the specific priorities for PLHIV in regards to social and economic support

In collaboration with the networks of PLHIV, determine the priorities for PLHIV in the country, with specific attention given to women, young people, and key populations living with HIV.

## 4 Assess the policy and systemic capacity to deliver social and economic support

- If a social and economic support policy or guideline is available, assess its HIV-sensitivity and determine if a specific policy or guideline is intended for PLHIV
- Given that social and economic support for PLHIV requires a multisectoral response, determine how the different sectors connected and whether and how they work together in the national response to HIV
- Determine what resources (e.g., human, service and financial) are available which deliver and provide social and economic support to the general population and what resources are specifically earmarked for PLHIV

## 5 Determine the gaps and strengths in social and economic support for PLHIV

Based on the outcomes from steps 1 to 4 above, you should be able to compare the results and determine the following:

- What support is available but not accessible to PLHIV?
- What support is not available but is a priority for PLHIV?
- What support is available, or could be accessible, to PLHIV. but does not allow for universal access due to inadequacies in the referral systems or other structural capacities?
- What factors and challenges influence the success

in meeting the social and economic support needs of PLHIV, identifying which are systemic/ structural and which are broader societal factors?

## Take follow-up steps to improve the level and quality of social and economic support for PLHIV

- Advocate for social and economic support of PLHIV
- Engage the local network of people living with HIV to determine the priority areas of support for PLHIV, women, young people and key populations in particular
- Mobilise political and organisational leadership for an effective multi-sectoral response
- Ensure the capacity for and resource a multisectoral coordination of the response to HIV, which may be possible through the CCM or the national AIDS committee
- Support community structures which are often the link between the different social protection and support sectors and services
- Adapt current policies to ensure the appropriate level of support to PLHIV and enforce protective policies and laws, such as those focused on employment and education, which will allow for greater access to PLHIV
- Develop HIV-specific social protection and support guidelines and policies
- Address systemic and structural enabling factors such as referral systems and the integration of services
- Meaningfully involve all sectors of society, including employees and trade unions, schools and educational institutions, social services, community support systems, civil society and key populations
- Address stigmatising attitudes and train those who provide social and economic support services
- Monitor progress and evaluate the impact

## **MEASURING IMPACT**

## 1 Map sources of evidence, M&E guidelines, and frameworks and processes, such as...

- PLHIV-driven evidence such as the PLHIV Stigma Index, Human Rights Count!, GIPA Report Card, and other methodologies (see www.gnpplus.net )
- PLHIV-focused guidelines for programming which will also include M&E guidance
- M&E guidelines and frameworks, including those on costing, planning and implementing an M&E framework
- Monitoring and reporting mechanisms (Global

- AIDS Response Progress Reports, Millennium Development Goal Progress Reports, etc.)
- Indicators and guidance on how to use them (e.g., UNAIDS M&E Reference Group, Global Fund Community Systems Strengthening, national lists, etc.)
- Processes and actions that result in evaluation reports on programmes and services, the impact of policies and laws, etc. (with recommendations on adaptations and improvements)

## 2 Assess the gaps and strengths of indicators...

- Capturing the reach and impact of programmes on all PLHIV, including key populations, socioeconomic demographics and characteristics, etc.
- Measuring the impact of processes (such as community engagement and PLHIV involvement) as well as service provision (such as coverage of ART and access by region and key population)
- Reporting from the direct attribution of action to results, in particular for advocacy and community engagement
- Measuring the impact of laws and policies (such as criminalisation laws or gender-equality protective laws) as well as direct service access (such as PLHIV accessing PMTCT services)
- Capturing evidence of progress beyond health outcomes only
- 3 Assess the successes and challenges related to reporting and accountability mechanisms, including...
- Resources available for M&E
- Capacity strengthening and training for M&E
- Availability of tools and guidelines for M&E
- Level of duplication or coordination of M&E from different systems (Global AIDS Response Reports, MDG Progress Reports, etc.)
- 4 Develop a comprehensive and inclusive M&E framework, which includes...
- Realistic costing and resourcing
- Capacity and skills strengthening actions
- The meaningful involvement of networks of PLHIV, civil society, key populations and communities

## Support PLHIV-driven evidence gathering and the meaningful participation of PLHIV in M&E...

- Through participation in the M&E of programmes at all stages
- Through PLHIV-driven research and M&E (For example, methodologies such as the PLHIV Stigma Index allows for determining a baseline of where the country is with regards to stigma faced by PLHIV, using this evidence to develop evidence-informed action, and then repeating the research to determine any changes due to the actions taken. The evidence not only contributes to measuring impact, but also enhances the capacity strengthening of networks of PLHIV and the meaningful participation and contribution to national M&E and accountability processes.)

## 6 Continuously learn from good policy and practice

- Develop a body of good policy and practice through the analysis of M&E evidence (see also Table 5 below)
- Share lessons learned within the country, across the region and internationally
- Assess and apply the lessons learned from other countries to national. local contexts

# ADDITIONAL SUGGESTED ACTIONS FOR NETWORKS

#### **PLANNING**

- It is important that the governance of the network understands and supports the concept of Positive Health, Dignity and Prevention and is supported in ensuring that the framework is embedded into the long-term strategic plan and the annual work-plans of the network.
- Evaluate your M&E, financial management, programme planning and management, and other organisational capacity (e.g., using Preventing HIV and Unintended Pregnancies Code of Good Practice self-assessments) and mobilise technical resources to strengthen capacities in areas where strengthening is needed.

#### **ADVOCACY**

- Advocate with the National AIDS Council, CCM, and other national coordinating bodies for the development and implementation of a Positive Health, Dignity and Prevention framework, embedded into the National Strategic Plan, and not an isolated, stand-alone initiative.
- Advocate for the meaningful involvement of people living with HIV at all stages and levels, and for support to ensure that participation is representative, is resourced, and protects the rights of those people living with HIV involved.
- Mobilise support from leaders in the response to HIV (politicians, parliamentarians, governmental representatives, community leaders, and technical experts, etc.)
- Develop communications materials on Positive Health, Dignity and Prevention that are targeted and specific.

## **DETERMINING PLHIV PRIORITIE**

- Develop plans to implement evidence-gathering tools and methodologies by and for PLHIV, (PLHIV Stigma Index, Human Rights Count!, Criminalisation Scan, SRHR Guidance Package, GIPA Report Card, etc.; see more at www.gnpplus.net and www.hivleadership. org) for generating evidence and using evidence for the advocacy and programme work of the network. These tools and methodologies can also support capacity strengthening in programme planning and management, partnership coordination, resource mobilisation, research skills and communications.
- Repeat evidence gathering of a methodology after 2 to 3 years and use evidence to 'evaluate' the impact of any policies and programmes that have been implemented since the first 'baseline' measurement.

#### **PARTNERSHIP**

- Engage in dialogue with civil society (in particular, with civil society coordination platforms where they exist) to ensure that civil society advocacy is centred on issues faced by PLHIV, and civil society partners support PLHIV engagement.
- Ensure that key populations living with HIV are included in your networks (governance, organisational structure, membership, programmes and advocacy work). If networks of key populations exist, develop partnerships to ensure that there is a coordinated response to the needs of the overlapping constituents -key populations living with HIV.
- Engage in dialogue with the local UNAIDS team (secretariat and cosponsors) which can offer invaluable support in initiating and coordinating communications with national stakeholders for Positive Health, Dignity and Prevention.
- Review existing and/or develop a new partnership strategy that is inclusive of all national stakeholders

#### **NATIONAL ENGAGEMENT**

- Develop a list of coordination systems and mechanisms in your country or region, and assess entry-points and opportunities for engagement of the network
- Develop a set of criteria, which will help you assess how your engagement as a network is meaningful. In other words, what would be the principles of quality engagement for your network?

#### **ENGAGEMENT OF PLHIV COMMUNITY**

- Inform your constituents on the Positive Health, Dignity and Prevention, using a language and terminology that is most appropriate for your national context.
- Raise treatment, health, legal and rights awareness for your constituents.
- Mobilise the people living with HIV community for support for Positive Health, Dignity and Prevention by supporting people living with HIV in understanding how they can be engaged in the response to HIV and how to ensure their engagement is meaningful.

# ADDITIONAL SUGGESTED ACTIONS FOR GOVERNMENT BODIES

#### **PLANNING**

- Develop a Positive Health, Dignity and Prevention framework that is part of (integrated) into your long-term strategic plan and annualworkplans (national or ministerial)
- If your work is specifically on HIV, ensure that there is coordination with activities of other departments (e.g., departments that address gender equality, SRHR, human rights, labour, etc.)
- If your work is not specific to HIV, ensure that there is coordination with the department that oversees your sector's response to HIV.

#### **ENGAGING PLHIV AND NETWORKS OF PLHIV**

- Evaluate the level and quality of engagement of PLHIV (in programmes' delivery, in your organisational management, in oversight of work) and determine what are the success factors and barriers in meaningful involvement.
- Evaluate the level and quality of engagement of the networks of PLHIV (in programmes' delivery, in oversight of work, partnership coordination, in joint-advocacy and policy development, etc.) and determine what are the success factors and barriers in meaningful involvement.
- Determine opportunities and quality criteria of engagement of PLHIV in partnership with networks of PLHIV.

#### POLITICAL AND ORGANISATIONAL LEADERSHIP

- Mobilise organisational support and leadership, in particular as adapting current work to be in line with Positive Health, Dignity and Prevention requires addressing policy and legal framework issues, addressing stigma within broader communities, and will require allocation of resources.
- Mobilise political support and leadership at high levels (Parliamentarians, Ministers, Heads of State, etc.)

#### MULTI-SECTORAL PARTNERSHIPS AND COORDINATION

Coordinate with other sectors' work. Positive Health, Dignity and Prevention requires addressing a diverse set of issues at the same time – health, social, legal, economic, education, etc. Coordination of actions will lead to greater efficiencies in use of resources and greater effectiveness in coherent and complementary programmes.

#### **PLHIV PRIORITIES**

- Determine priority areas based on evidence of current experiences of all people living with HIV, in particular key populations living with HIV. Networks of PLHIV are an invaluable source of information and evidence.
- Use evidence from and/or support the implementation of PLHIV Stigma Index, Human Rights Count!, SRHR Guidance Package, GIPA Report Card and Criminalisation Scan to evaluate next steps in implementation.
- Where evidence is lacking, gather evidence in partnership with networks of people living with HIV.

# ADDITIONAL SUGGESTED ACTIONS FOR CIVIL SOCIETY ORGANISATIONS

#### **PLANNING**

- Develop a Positive Health, Dignity and Prevention framework that is part of (integrated) into your long-term strategic plan and annual workplans

#### ENGAGING PLHIV AND NETWORKS OF PLHIV

- Engage as partners in the implementation of PLHIV-led evidence gathering (e.g., PLHIV Stigma Index, Human Rights Count!, etc.)
- Engage networks of PLHIV in your advocacy work, and ensure that messages are coordinated and coherent.
- Evaluate the level and quality of engagement of PLHIV (in programmes' delivery, in your organisational management, in governance) and determine what are the success factors and barriers in meaningful involvement.
- Evaluate the level and quality of engagement of the networks of PLHIV (in programmes' delivery, as partners, in joint-advocacy and policy development, in governance, etc.) and determine what are the success factors and barriers in meaningful involvement

## POLITICAL AND ORGANISATIONAL LEADERSHIP

- Mobilise organisational support and leadership, in particular as adapting current work to be in line with Positive Health, Dignity and Prevention requires addressing policy and legal framework issues, addressing stigma within broader communities, and will require allocation of resources.
- Mobilise political support and leadership at high levels (Parliamentarians, Ministers, Heads of State, etc.)

#### ADVOCACY AND MOBILISATION OF SUPPORT

- Support the networks of PLHIV in their advocacy for Positive Health, Dignity and Prevention and ensure coordination of messages.
- Mobilise leadership within the civil society stakeholders response to HIV
- Develop evidence-informed and PLHIVcentred advocacy and actions

#### **ACCOUNTABILITY**

- Engage in accountability mechanisms (e.g., UNGASS and MDG reporting) using the Positive Health, Dignity and Prevention framework and concept
- Use evidence on PLHIV experiences gathered by networks of PLHIV (e.g., PLHIV Stigma Index) to support your work on national response accountability
- Support the networks of PLHIV to engage in accountability processes

### ADDITIONAL SUGGESTED ACTIONS FOR NATIONAL COORDINATING BODIES

### **PLANNING**

- Develop a Positive Health, Dignity and Prevention framework that is part of (integrated) into the longterm strategic plan and annual-workplans

### ENGAGING PLHIV AND NETWORKS OF PLHIV

- Evaluate the level and quality of engagement of networks of PLHIV in the coordination (in programmes' delivery, in oversight of work, partners, recipients of resources, in joint policy formulation, etc.) and determine what are the success factors and barriers in meaningful involvement.
- If PLHIV are engaged that are not members of networks, determine how representativeness is maintained and support involved people living with HIV in their leadership position
- Determine opportunities and quality criteria of engagement of PLHIV in partnership with networks of PLHIV, and embed these quality criteria into your coordination's terms of reference.

### **ACCOUNTABILITY**

Use evidence from and/or support the implementation of PLHIV Stigma Index, Human Rights Count!, SRHR Guidance Package, GIPA Report Card and Criminalisation Scan as a way to support your work in coordinating, monitoring and evaluating the national response to HIV.

### **RESOURCES**

- Allocate resources for the capacity strengthening of networks of PLHIV
- Eliminate resource-related barriers for PLHIV and PLHIV engagement in coordination (e.g., travel related and communications costs)
- Mobilise resources for Positive Health, Dignity and Prevention in partnership with networks of PLHIV
- Advocate for allocation of resources for Positive Health, Dignity and Prevention through sectoral plans and budgets.

### ADDITIONAL SUGGESTED ACTIONS FOR DONORS AND DEVELOPMENT AGENCIES

### **PLANNING**

- Develop a Positive Health, Dignity and Prevention framework that is part of (integrated) into the longterm strategic plan and annual-workplans

### ENGAGING PLHIV AND NETWORKS OF PLHIV

- Evaluate the level and quality of engagement of networks of PLHIV in the coordination (in programmes' delivery, in oversight of work, partners, recipients of resources, in joint policy formulation, etc.) and determine what are the success factors and barriers in meaningful involvement.
- If PLHIV are engaged that are not members of networks, determine how representativeness is maintained and support involved people living with HIV in their leadership position
- Determine opportunities and quality criteria of engagement of PLHIV in partnership with networks of PLHIV, and embed these quality criteria into your coordination's terms of reference.

### **ACCOUNTABILITY**

Use evidence from and/or support the implementation of PLHIV Stigma Index, Human Rights Count!, SRHR Guidance Package, GIPA Report Card and Criminalisation Scan as a way to support your work in coordinating, monitoring and evaluating the national response to HIV.

### **RESOURCES**

- Allocate resources for the capacity strengthening of networks of PLHIV
- Eliminate resource-related barriers for PLHIV and PLHIV engagement in coordination (e.g., travel related and communications costs)
- Mobilise resources for Positive Health, Dignity and Prevention in partnership with networks of PLHIV
- Advocate for allocation of resources for Positive Health, Dignity and Prevention through sectoral plans and budgets.

### ANNEX 7: **INDICATORS**

This section lists some of the key indicators found in key HIV-related M&E guidance. In particular, the following resources were reviewed in order to select key indicators that are as much as possible directly related to Positive Health, Dignity and Prevention:

### **GARPR**

UNAIDS. 2011. Global AIDS Response Progress Reporting 2012 Guidelines: Construction of Core Indicators for Monitoring the 2011 Political Declaration on HIV/AIDS. http://www.unaids.org/en/dataanalysis/monitoringcountryprogress/ globalaidsprogressreport/

### **GLOBAL FUND HIV**

Global Fund. 2011. Monitoring and Evaluation Toolkit: HIV, Tuberculosis, Malaria and Health and Community Systems Strengthening (Part 2: HIV). (4th ed.).

http://www.theglobalfund.org/en/me/documents/toolkit/

### GLOBAL FUND COMMUNITY SYSTEMS STRENGTHENING (CSS)

Global Fund. 2011. Monitoring and Evaluation Toolkit: HIV, Tuberculosis, Malaria and Health and Community Systems Strengthening (Part 5: Health and Community Systems Strengthening).

http://www.theglobalfund.org/en/me/documents/toolkit/

### **GNP+ POSITIVE HEALTH, DIGNITY AND PREVENTION QUESTIONNAIRE**

GNP+. 2011. Positive Health, Dignity and Prevention Questionnaire. Interview for people living with HIV, ages 15 to 60 in Tanzania.

GNP+. 2011. Positive Health, Dignity and Prevention Questionnaire. Encuesta para personas que viven con el VIH, de entre 15 y 65 años, en Bolivia [Interview for people living with HIV, ages 15 to 60 in Bolivia].

GNP+. 2011. Positive Health, Dignity and Prevention Questionnaire. Indicator tables from Vietnam.

### **GARPR: NCPI**

UNAIDS. 2011. Global AIDS Response Progress Reporting 2012 Guidelines: Construction of Core Indicators for Monitoring the 2011 Political Declaration on HIV/AIDS. Appendix 3: National Commitments and Policy Instrument (NCPI) 2012.

http://www.unaids.org/en/dataanalysis/monitoringcountryprogress/ globalaidsprogressreport/

### **PEPFAR**

PEPFAR. 2009. Next Generation Indicators Reference Guidance Version 1.1.

http://www.pepfar.gov/reports/guidance/c21628.htm

### **NETWORK CAPACITY ANALYSIS**

International HIV/AIDS Alliance. 2007. Network Capacity Analysis: A toolkit for assessing and building capacities for high quality responses to HIV.

http://www.aidsalliance.org/publicationsdetails.aspx?id=278

### **PLHIV STIGMA INDEX**

The People Living with HIV Stigma Index. 2008. Ouestionnaire.

### **UNESCO**

UNESCO. 2012, July. Global Monitoring & Evaluation Framework for Comprehensive Education Responses to HIV and AIDS: Proposed Indicators. Draft for field test.

### DHS

USAID. 2010. Questionnaires: Household, Woman's, and Man's. Demographic and Health Surveys Methodology.

### **GLOBAL FUND TB**

Global Fund. 2011. Monitoring and Evaluation Toolkit: HIV, Tuberculosis, Malaria and Health and Community Systems Strengthening (Part 3: Tuberculosis).

### **GIPA REPORT CARD**

GNP+. 2009. GIPA Report Card Questionnaire. Millennium Development Goals (MDG) Indicators Inter-agency and Expert Group (IAEG) on MDG Indicators. 2008. Official list of MDG indicators.

### **MICS**

MICS4. 2012. Indicators: Numerators and Denominators.

### **UNGASS**

UNAIDS. 2009. Monitoring the Declaration of Commitment on HIV/AIDS. Guidelines on Construction of Core Indicators: 2010 reporting.

UNAIDS. 2008. Core Indicators for National AIDS Programmes. Guidance and Specifications for Additional Recommended Indicators. www.IndicatorRegistry.org

Some components and sub-components of Positive Health, Dignity and Prevention currently lack appropriate indicators. This is an area which clearly requires further work. UNAIDS and GNP+ will be using the opportunities of country-level testing of these Operational Guidelines to expand the Indicators table as much as possible, as well as engage in more direct work on M&E and Positive Health, Dignity and Prevention. Where current gaps exist they are noted under each Component.

### **EMPOWERMENT OF PLHIV AND NETWORKS OF PLHIV**

INDICATOR	TYPE OF	COLIDGE
COMPONENT: A.2. MEANINGFUL INVOLVEMENT OF PLHIV	INDICATOR	SOURCE
Percentage of PLHIV who belongs to any civil society or empowerment group(s) and are involved in at least 2 activities in this group	Input	GNP+ Positive Health, Dignity and Prevention Questionaire
Percentage of PLHIV who have provided at least 2 forms of support to PLHIV in past 12 months	Input	GNP+ Positive Health, Dignity and Prevention Questionaire
Number and percentage of community-based organizations that deliver services for HIV, TB, malaria and immunization according to national or international accepted service delivery standards (7.1)	Output	Global Fund CSS
COMPONENT: A.3. CAPACITY BUILDING OF PLHIV NETWORKS		
Number and percentage of community-based organizations that received technical support for institutional strengthening in accordance with their requests the last 12 months	Output	Global Fund CSS
Number and percentage of community health workers currently working with community-based organizations who received training or re-training in HIV, TB, malaria or immunization service delivery according to national guidelines (where such guidelines exist) during the last national reporting period	Output	Global Fund CSS
Number and percentage of community-based organizations that have core funding secured for at least 2 years	Output	Global Fund CSS
Number and percentage of community-based organizations that have a complete and sound financial management system, which is known and understood by staff and consistently adhered to	Output	Global Fund CSS
COMPONENT: A.4. PLHIV LEADERSHIP DEVELOPMENT		
Percentage of PLHIV who have been involved in at least 1 activity to support law/policy development for PLHIV	Input	GNP+ Positive Health, Dignity and Prevention Questionaire
Number and percentage of community based organizations with staff in managerial positions who received training or re-training in management, leadership or accountability during the last reporting period	Output	Global Fund CSS
COMPONENT: A.5. PLHIV LEADERSHIP DEVELOPMENT		
Percentage of PLHIV who know of at least 2 or more organizations that provide support	Input	GNP+ Positive Health, Dignity and Prevention Questionaire



### **QUALITATIVE INDICATES (NCPI SECTION OF GARPR**

### COMPONENT: A.2. MEANINGFUL INVOLVEMENT OF PLHIV

To what extent (on a scale of 0 to 5 where 0 is "Low" and 5 is "High") have civil society representatives been involved in the planning and budgeting process for the National Strategic Plan on HIV or for the most current activity plan (e.g. attending planning meetings and reviewing drafts)?

To what extent (on a scale of 0 to 5 where 0 is "Low" and 5 is "High") is civil society included in the monitoring and evaluation (M&E) of the HIV response? a. Developing the national M&E plan? b. Participating in the national M&E committee / working group responsible for coordination of M&E activities? c. Participate in using data for decision-making?

Has the Government, through political and financial support, involved people living with HIV, key populations and/or other vulnerable sub-populations in governmental HIV-policy design and programme implementation?

### COMPONENT A.6 PLHIV LEGAL, RIGHTS AND HEALTH LITERACY

Does the country have a policy or strategy to promote information, education and communication and other preventive health interventions for key or other vulnerable sub-populations? Yes /No (describe the content of this policy or strategy) IF YES, which populations and what elements of HIV prevention does the policy/strategy address?

	IDU	MSM	SEX WORKERS	CLIENTS OF SEX WORKERS	PRISON INMATES	PHLIV	OTHER POPULATIONS (write in)
Condom promotion							
Drug substitution therapy							
HIV testing and counseling							
Needle & syringe exchange							
Reproductive health, including sexually transmitted infections prevention and							
Stigma and discrimination reduction							
Targeted information on risk reduction and HIV education							
Vulnerability reduction (e.g. income generation)							

### **HEALTH PROMOTION AND ACCES**

INDICATOR	TYPE OF INDICATOR	SOURCE
COMPONENT: B.1 TREATMENT ACCESS FOR PLHIV		
Percentage of adults and children with HIV known to be on treatment 12 months after initiation of antiretroviral therapy	Impact	GARPR
Percentage of MSM - People who inject drugs - Sex workers - Women and men aged 15-49 who received an HIV test in the past 12 months and know their results	Coverage	GARPR
Percentage of eligible adults and children currently receiving antiretroviral therapy	Output	GARPR
Percentage of PLHIV who have had CD4 count taken after diagnosis	Output	GNP+ Positive Health, Dignity and Prevention Questionaire
COMPONENT: B.2 CARE AND SUPPORT OF PLHIV		
Number and percentage of undernourished people living with HIV who received therapeutic or supplementary food at any point during the reporting period	Output	Global Fund HIV
Number of adults and children living with HIV who receive care and support services outside facilities	Output	Global Fund HIV
COMPONENT: B.3 PREVENTION, DIAGNOSIS AND TREATMENT OF OTHER INFECTIONS AND ILLNESSES FOR PLHIV		
Number and percentage of adults and children enrolled in HIV care and eligible for co-trimoxazole prophylaxis (according to national guidelines) currently receiving co-trimoxazole prophylaxis	Output	PEPFAR
Percentage of estimated HIV-positive incident TB cases that received treatment for both TB and HIV	Output	GARPR
Number and percentage of adults and children enrolled in HIV care who had TB status assessed and recorded during their last visit among all adults and children enrolled in HIV care in the reporting period	Output	Global Fund HIV
Number and percentage of adults and children newly enrolled in HIV care who start treatment for latent TB infection (isoniazid preventive therapy) among the total number of adults and children newly enrolled in HIV care over a given time period	Output	Global Fund HIV

Note: There exists a gap in appropriate indicators for Component: b.4 Quality assurance and improvement of health services for PLHIV

### **GENDER EQUALITY**

INDICATOR	TYPE OF INDICATOR	SOURCE
COMPONENT: C.3 EMPOWERMENT OF COMMUNITIES AND INDIVIDUALS		
Percentage of PLHIV who have ever taken positive action to respond to gender-related negative situation (filed complaint, sought help, etc.)	Outcome	GNP+ Positive Health, Dignity and Prevention Questionaire
Network capacity index for networks of organizations promoting women's rights	Input	Network Capacity Analysis
Network capacity index for networks of organizations promoting LGBTI people rights	Input	Network Capacity Analysis
COMPONENT: C.4 SOCIAL DRIVERS AND GENERAL PUBLIC		
Percentage of PLHIV who have never experienced negative situation (including abuse, denial of support, etc) after HIV diagnosis because of their gender	Outcome	GNP+ Positive Health, Dignity and Prevention Questionaire
Percentage of PLHIV who never experienced any discriminatory experience in the past 12 months	Outcome	GNP+ Positive Health, Dignity and Prevention Ouestionaire

Note: There exist gap in appropriate indicators for Component: c.1 Centralised and Systemic Responses and Component: c.2 Service Provision

### **HUMAN RIGHTS**

	-V25- 05	
INDICATOR	TYPE OF INDICATOR	SOURCE
COMPONENT: D.1 LEGAL AND POLICY REFORM AND ENFORCEMENT		
Percentage of PLHIV who have been involved in any efforts to develop legislation, policies or guidelines related to HIV in the last 12 months	Input	PLHIV Stigma Index
Percentage of PLHIV who accessed free legal services	Coverage	GNP+ Positive Health, Dignity and Prevention Questionaire
COMPONENT: D.2 SOCIAL CHANGE AND EMPOWERMENT		
Percentage of PLHIV who knows their rights as a person living with HIV	Outcome	GNP+ Positive Health, Dignity and Prevention Questionaire
Percentage of PLHIV having experienced stigma or discrimination from other people in the last 12 month because of their belonging to a key population	Outcome	PLHIV Stigma Index
Percentage of PLHIV who had at least one of their rights abused in the last 12 months because of their HIV status	Outcome	PLHIV Stigma Index
Percentage of PLHIV having internal stigma in the last 12 month because of their HIV status	Outcome	PLHIV Stigma Index
Percentage of women and men aged 15–49 years expressing accepting attitudes towards people living with HIV	Outcome	Global Fund HIV
COMPONENT: D.3 MONITORING AND RESPONDING TO HUMAN RIGHTS VIOLATIONS		
Percentage of PLHIV who have confronted, challenged or educated someone who was stigmatizing and/or discriminating against them In the last 12 months	Input	PLHIV Stigma Index
Percentage of PLHIV whose legal action has been satisfactorily addressed (among those who had at least one of their rights abused) in the last 12 months	Outcome	PLHIV Stigma Index

### PREVENTION FROM NEW INFECTIONS

TYPE OF INDICATOR	SOURCE
Coverage	GARPR
Outcome	GARPR
Outcome	GNP+ Positive Health, Dignity and Prevention Questionaire
Coverage	GARPR
Output	GARPR
Output	PEPFAR
Output	Global Fund HIV
Output	Global Fund HIV
	Coverage  Outcome  Outcome





### QUALITATIVE INDICATES (NCPI SECTION OF GARPR)

### COMPONENT: E.1 COMPREHENSIVE EDUCATION THAT FOSTERS SHARED RESPONSIBILITY

Does the country have a policy or strategy that promotes information, education and communication (IEC) on HIV to the general population?

Does the country have a policy or strategy to promote information, education and communication and other preventive health interventions for key or other vulnerable sub-populations?

IF YES, which populations and what elements of HIV prevention does the policy/strategy address? Condom promotion, Drug substitution therapy, HIV testing and counselling, Needle & syringe exchange, Reproductive health including sexually transmitted infections, prevention and treatment, Stigma and discrimination reduction, Targeted information on risk reduction and HIV education, Vulnerability reduction (e.g. income generation)

Note: There exists a gap in appropriate indicators for Component: Component e.4 - ART and treatment for prevention and Component e.5 - Support for sero-different couples

### SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS

INDICATOR	TYPE OF INDICATOR	SOURCE
COMPONENT: F.1 SEXUAL HEALTH AND WELL-BEING		
Percentage of PLHIV who have not had an STI since diagnosed HIV-positive (of those who are currently sexually active)	Outcome	Global Fund HIV
Percentage of PLHIV who discussed 3 or more sexual health issues with a professional counsellor	Output	GNP+ Positive Health, Dignity and Prevention Questionnaire
Percentage of PLHIV who received information on at least 1 option for having children as a person with HIV	Output	GNP+ Positive Health, Dignity and Prevention Questionaire
COMPONENT: F.2 REPRODUCTIVE HEALTH		
Percentage of HIV positive women using a modern family planning method	Output	Global Fund HIV
Percentage of PLHIV who received information of effects of ARVs on both baby and the mother (of those who wish to have children in the future)	Output	GNP+ Positive Health, Dignity and Prevention Questionnaire
COMPONENT: E 3 SEX AND SEXUALITY		
Percentage of schools that provided life skills-based HIV and sexuality education within the previous academic year	Output	UNESCO
Percentage of PLHIV who received at least 7 or more important messages from health care professionals about management of sexual life	Output	GNP+ Positive Health, Dignity and Prevention Questionnaire
COMPONENT: F.4 SRHR AS HUMAN RIGHTS		
Percentage of PLHIV who have been denied sexual and reproductive health services because of their HIV status	Outcome	PLHIV Stigma Index

### **SOCIAL PROTECTION**

INDICATOR	TYPE OF INDICATOR	SOURCE
COMPONENT: G.1 EMPLOYMENT AND ECONOMIC EMPOWERMENT		
Percentage of educational institutions that implement an HIV Workplace programme	Output	UNESCO
COMPONENT: G.2 SOCIAL PROTECTION		
Current school attendance among young PLHIV aged 10-14 years	Output	GNP+ Positive Health, Dignity and Prevention Questionaire
Current school attendance among orphans and non-orphans aged 10–14	Output	GARPR
Percentage of orphaned and vulnerable children, aged 5-17 years, who receive bursary support through schools	Output	UNESCO
Percentage of orphaned and vulnerable children, aged 5-17 years, who receive emotional/psychological support through schools	Output	UNESCO
Percentage of orphaned and vulnerable children, aged 5-17 years, who receive social support, excluding bursary support, through schools	Output	UNESCO
COMPONENT: G.4 HEALTHY LIVING CONDITIONS		
Proportion of eligible households who received external economic support in the last 3 months	Output	GARPR
Number and percentage of HIV affected households that receive food security services	Output	Global Fund HIV

Note: There exists a gap in appropriate indicators for Component: g.3 Support for caregivers

### **MEASURING IMPACT**

INDICATOR	TYPE OF INDICATOR	SOURCE
Number and percentage of community-based organizations using standard data collection tools and reporting formats to report to the national reporting system (9.4)	Input	Global Fund CSS
Number and percentage of community-based organizations that submit timely, complete and accurate financial and programmatic reports to the national level according to nationally or internationally recommended standards and guidelines (where such guidelines exist) (9.1)	Output	Global Fund CSS
Percentage of sex workers who are living with HIV	Impact	GARPR
Percentage of men who have sex with men who are living with HIV	Impact	GARPR
Percentage of people who inject drugs who are living with HIV	Impact	GARPR
Percentage of young people aged 15-24 who are living with HIV	Impact	GARPR

### QUALITATIVE INDICATES (NCPI SECTION OF GARPR)

### COMPONENT: E.1 COMPREHENSIVE EDUCATION THAT FOSTERS SHARED RESPONSIBILITY

Does the country have one national Monitoring and Evaluation (M&E) plan for HIV? IF YES, have key partners aligned and harmonized their M&E requirements (including indicators) with the national M&E plan?

Is there a central national database with HIV- related data? IF YES, does it include information about the content, key populations and geographical coverage of HIV services, as well as their implementing organizations?

Does the multisectoral strategy or operational plan include: a) Formal programme goals? b) Clear targets or milestones? c) Detailed costs for each programmatic area? d) An indication of funding sources to support programme implementation? e) A monitoring and evaluation framework?

In the last year, was training in M&E conducted? Were other M&E capacity-building activities conducted other than training? If yes, describe what types of activities

To what extent (on a scale of 0 to 5 where 0 is "Low" and 5 is "High") is civil society included in the monitoring and evaluation (M&E) of the HIV response?

# TABLE 1 MAPPING PARTNERS AND ACTIONS FOR OPERATIONALIZATION

	ACTIONS WITHI	ACTIONS WITHIN THE FRAMEWORK OF POSITIVE HEALTH, DIGNITY AND PREVENTION	K OF POSITIVE HE	ALTH, DIGNITY AN	ND PREVENTION		
COMPONENT	Information sharing / Networking / Advocacy for mobilisation / social mobilisation	Specific programmes and services / skills development and strengthening	Advocacy and policy development and legal reform	Resources and resource mobilisation (technical, funds, systems, etc.)	Other	Partners	How are networks of PLHIV and PLHIV
POSITIVE HEALTH, DIGNITY AND PREVENTION PL		ANNING AND MANAGEMENT	AGEMENT				
Strategy and work-planning							
Evidence							
Advocacy and mobilisation							
Coordination							
M&E							
Adaptation and improvement							
EMPOWERMENT OF PLHIV AND NETWORKS OF PLHIV	NETWORKS OF PL	HIV					
Meaningful involvement of Networks of PLHIV							
Meaningful involvement of PLHIV							
Capacity building of Networks of PLHIV							
PLHIV leadership development							
PLHIV legal, rights and health literacy							
HEALTH AND ACCESS PROMOTION FOR PLHIV	ON FOR PLHIV						
Treatment access for PLHIV							
Care and support of PLHIV							
Prevention, diagnosis and treatment of other infections and illnesses for PLHIV							
Quality assurance of health services for PLHIV							

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	ACTIONS WITHII	HIN THE FRAMEWORK OF POSITIVE HEALTH, DIGNITY AND PREVENTION	IK OF POSITIVE HE	ALTH, DIGNITY AI	ND PREVENTION		
COMPONENT	Information sharing / Networking / Advocacy for mobilisation / social mobilisation	Specific programmes and services / skills development and strengthening	Advocacy and policy development and legal reform	Resources and resource mobilisation (technical, funds, systems, etc.)	Other	Partners	How are networks of PLHIV and PLHIV
GENDER EQUALITY OF PLHIV							
Central and systemic responses							
Service provision							
Empowerment							
Social drivers							
HUMAN RIGHTS OF PLHIV							
Legal, policy reform and enforcement							
Social change and empowerment							
Monitoring and responding to human rights violations							
PREVENTION OF NEW INFECTIONS	NS.						
Comprehensive education that fosters shared responsibility							
Access to prevention technologies							
Universal access to prevention of new infections in children							
ART and treatment for prevention							
Support for sero-different couples							
SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS OF PLHIV	ALTH AND RIGHT	S OF PLHIV					
Sexual health and well-being							
Reproductive health							
Sex and sexuality							
Sexual and Reproductive Health Rights as human rights							



	ACTIONS WITHI	ACTIONS WITHIN THE FRAMEWORK OF POSITIVE HEALTH, DIGNITY AND PREVENTION	K OF POSITIVE HE	ALTH, DIGNITY A	ND PREVENTION		
COMPONENT	Information sharing / Networking / Advocacy for mobilisation / social mobilisation	Specific programmes and services / skills development and strengthening	Advocacy and policy development and legal reform	Resources and resource mobilisation (technical, funds, systems, etc.)	Other	Partners	How are networks of PLHIV and PLHIV involved?
SOCIAL AND ECONOMIC SUPPORT FOR PLHIV	RT FOR PLHIV						
Employment and economic empowerment							
Social protection							
Support for caregivers							
Healthy living conditions							
MEASURING IMPACT OF POSITIVE HEALTH, DIGNIT	E HEALTH, DIGNIT	<b>LY AND PREVENTION</b>	NO				
Evidence generation and use with the participation and leadership of PLHIV							
Developing and/or using existing indicators for evaluating impact							
Monitoring, evaluating and adapting programmes based on evidence and lessons learned							
Developing a body of good policy and programme practice							



## TABLE 2 MAPPING STRUCTURES, SYSTEMS AND STAKEHOLDERS

STRUCTURE / SYSTEM / COORDINATING BODY TITLE	Goal / Purpose / Aim	Role in policy and strategy	Role in services and programmes	Role in coordination and monitoring and accountability	Role in advocacy and policy change	How are PLHIV involved?	How are networks of PLHIV involved?	Who are the main partners, and who leads?
National response to HIV level 1 National AIDS Council/ Commission 2 CCM 3								
Ministerial/Sectoral level systems/ coordination 1 Health 2 Labour 3 Education 4 Social protection 5								
Governmental bodies 1 2 3								
Political and Parliamentarian unions 1 2 3								
Civil society coordinating bodies 1 2 3								

STRUCTURE / SYSTEM / COORDINATING BODY TITLE	Goal / Purpose / Aim	Role in policy and strategy	Role in services and programmes	Role in coordination and monitoring and accountability	Role in advocacy and policy change	How are PLHIV involved?	How are networks of PLHIV involved?	Who are the main partners, and who leads?
Donors and development agencies coordination 1 2								
Private sector coalitions on HIV 1 2 3								
Research and M&E 1 2 3								
Other 1								



### TABLE 3 POLICY AND LEGAL ENVIRONMENT ASSESSMENT

IS THERE A SPECIFIC PART OF THE POLICY ENFORCED? LAW FOR LAW FOR - PLHIV? - Punitive? - Criminalising? - How functioning are there saystems?												
WHAT IS THE CURRENT STATUS?  - Does such a law/ policy exist? - What are the main points? - How is it currently used/applied or not? What is t												
SUBJECT OF POLICY OR LAW	Access to ARV treatment	Access to PMTCT	Access to health	Travel, residence and stay restrictions for PLHIV	M&E	Adaptation and improvement	Meaningful involvement of Networks of PLHIV	Employment rights	Criminalisation of HIV non-disclosure, transmission and exposure laws	Sex worker rights	People who use drugs rights	



SUBJECT OF POLICY OR LAW	WHAT IS THE CURRENT STATUS?  - Does such a law/ policy exist?  - What are the main points?  - How is it currently used/applied or not?	IS THERE A SPECIFIC PART OF THE POLICY/ LAW FOR - PLHIV? - Punitive? - Criminalising? What is the impact on PLHIV?	WHAT IS THE IMPACT FOR KEY POPULATIONS? Protective? Punitive? Criminalising? And how does it link with PLHIV?	HOW IS THIS LAW/ POLICY ENFORCED?  - Is there a body that coordinates its monitoring?  - Are there any systems that PLHIV can use for rights protections?  - How functioning are these systems?	WHAT ARE THE CURRENT EFFORTS FOR: - Reform? - Skills building? - Other? And who is leading the process?
Gender equality					
SRHR					
Civil society participation in national issues					
Social protection					
Education					
Immigration					
Prisoner rights					



TABLE 4 PLHIV POPULATION AND % COVERAGE FOR TREATMENT, PREVENTION, CARE AND SUPPORT

		% COVERAGE I	COVERAGE BY DEMOGRAPHICS OF PLHIV	HICS OF PLHIV				
DEMOGRAPHICS	PLHIV population	ART access	Prevention technologies	SRHR-related services and literacy	PMTCT	Care and support	STI diagnosis and treatment	Co-infections diagnosis and treatment
AGE								
0-4								
5-9								
10-14								
15-19								
20-24								
25-29								
30-34								
35-39								
40-44								
45-49								
50-54								
55-59								
09<								
SEX								
Female								
Male								
Transgender								
Transsexual								

		% COVERAGE I	COVERAGE BY DEMOGRAPHICS OF PLHIV	HICS OF PLHIV				
DEMOGRAPHICS	PLHIV population	ART access	Prevention technologies	SRHR-related services and literacy	PMTCT	Care and support	STI diagnosis and treatment	Co-infections diagnosis and treatment
LOCATION								
Urban								
Rural								
By district / province								
<del></del>								
2								
3								
4								
5								
HIGHEST LEVEL OF EDUCATION ATTAINED	ON ATTAINED							
No formal education								
Primary school								
Secondary school								
Technical college / university								
Post-graduate								
<b>EMPLOYMENT STATUS</b>								
In full-time employment								
In part-time employment								
Unemployed								
Housework								
Student								
Retired								
Disabled, not able to work								
Other								



		% COVERAGE B	% COVERAGE BY DEMOGRAPHICS OF PLHIV	IICS OF PLHIV				
DEMOGRAPHICS	PLHIV population	ART access	Prevention technologies	SRHR-related services and literacy	PMTCT	Care and support	STI diagnosis and treatment	Co-infections diagnosis and treatment
KEY POPULATION LIVING WITH HIV	н ніу							
MSM								
Migrant or migrant worker								
People who use drugs								
Prisoners								
Refugee or asylum seekers								
Sex workers								
Transgender								
Women								
Young person LHIV								
Other								



### **USEFUL RESOURCES AND REFERENCES**

### POSITIVE HEALTH, DIGNITY AND PREVENTION **RESOURCES**

- GNP+, UNAIDS. 2011. Positive Health, Dignity and Prevention: A Policy Framework.
- GNP+, UNAIDS. 2009. Technical Consultation Report: Positive Health, Dignity and Prevention. Tunis, April 2009.
- · Asia Pacific Network of People Living with HIV (APN+). 2009. Positive Health (Positive Health, Dignity and Prevention): Moving the agenda forward in the Asia Pacific Region. Satellite meeting at the 9th International Congress on AIDS in Asia and the Pacific, Bali, Indonesia, August 2009. (December 2009).
- GNP+, UNAIDS, Sidaction. 2010. Santé Positive. Dignité et Prévention: Rapport de Consultation (Positive Health, Dignity and Prevention Consultation Report). Casablanca, Morocco March 28, 2010.
- INP+. 2010. National Level Consultation on Positive Prevention, New Delhi, February 2010.

### PLHIV-DRIVEN AND -RELATED **EVIDENCE GATHERING RESOURCES**

### POSITIVE HEALTH, DIGNITY AND PREVENTION **OPERATIONAL RESEARCH**

GNP+ is in the process of finalising a methodology and tool that measures the experiences, needs and barriers of people living with HIV in relation to the components of Positive Health, Dignity and Prevention. The methodology is guided by pilot (2009-2010) research carried out in partnership with networks of people living with HIV in Bolivia (Redbol+), Tanzania (NACOPHA) and Vietnam (VNP+), the Population Council and UNAIDS. Using personal digital assistants (PDAs), people living with HIV are research coordinators, supervisors, data collectors and interviewees, leading the process from the development of a context-specific questionnaire, through to data collection, analysis of findings, report writing and advocacy. The studies on Positive Health, Dignity and Prevention will provide networks of people living with HIV with information to evaluate country-specific progress in providing a supportive and enabling environment for people living with HIV to take care of themselves, their partners and their communities. The information gathered by people living with HIV will inform the development and implementation of national policies and programmes on HIV prevention as it relates to people living with HIV.

http://www.gnpplus.net/evidence/phdp-operational-research/

### THE PEOPLE LIVING WITH HIV STIGMA INDEX

The People Living with HIV Stigma Index is a joint initiative of organisations that have worked together since 2004 to develop this survey, including GNP+, ICW, IPPF, and UNAIDS. The People Living with HIV Stigma Index provides a tool that measures and detects changing trends in relation to stigma and discrimination experienced by people living with HIV. In the initiative, the process is just as important as the product. It aims to address stigma relating to HIV while also advocating on the key barriers and issues perpetuating stigma — a key obstacle to HIV treatment, prevention, care and support.

www.stigmaindex.org www.gnpplus.net/en/programmes/human-rights/ plhiv-stigma-index

### THE GIPA REPORT CARD

The GIPA Report Card (developed by GNP+, ICW, UNAIDS) identifies existing levels of the application of the GIPA principle at the country level and provides insights on how the participation of people living with HIV can be made more meaningful.

http://www.gnpplus.net/evidence/gipa-report-card/

### GLOBAL CRIMINALISATION SCAN

Since 2008, the Global Criminalisation Scan (developed by GNP+ and regional networks of people living with HIV) has documented existing legislation that criminalises HIV non-disclosure, exposure, and transmission, as well as cases when these and non-HIV-specific laws have been used to prosecute individuals living with HIV. The aim of this in-depth research is to develop methodologies for national networks of PLHIV to develop evidence-informed strategies to respond to criminalisation, and to create a pool of knowledge that will inform advocacy plans and can be shared with other jurisdictions.

www.gnpplus.net/criminalisation

### **HUMAN RIGHTS COUNT!**

Human Rights Count! (developed by GNP+ and regional networks of people living with HIV) is an evidencegathering tool that documents cases of HIV-related human rights violations experienced by women, men, and excluded individuals living with HIV. The methodology documents the circumstances behind violations and follow-up actions to confront or redress. Its overall aim is to decrease the number of these human rights violations by using the information gathered to guide advocacy campaigns.

http://www.gnpplus.net/evidence/human-rights-count/

### GLOBAL DATABASE ON HIV-SPECIFIC TRAVEL AND RESIDENCE RESTRICTIONS

The Global Database on HIV-Specific Travel and Residence Restrictions provides updated information from 196 countries on existing regulations denying entry or residency for people living with HIV based on relevant country legislation. The database serves as a regularly updated source of information, mapping the evolution of HIVtravel restrictions globally, functioning as a a mechanism for monitoring HIV-related travel restrictions and their impact, and serving as a publicly available tool for advocacy, policy and international accountability initiatives, as well as to inform personal travel and migration. Wherever possible, the database provides information about the mechanisms used in practice to support implementation and enforcement of HIV-related travel restrictions. An initiative of Deutsche AIDS-Hilfe (DAH), the European AIDS Treatment Group (EATG), and the International AIDS Society (IAS), the database builds on DAH's preliminary work on travel and entry regulations for people living with HIV and is a successor to earlier information provided on the EATG website.

www.hivtravel.org

### TREATMENT MONITORING AND ADVOCACY PROJECT (TMAP)

Launched in 2005 by the International Treatment Preparedness Coalition (ITPC), TMAP identifies barriers to the delivery of HIV services and holds national governments and global institutions accountable for improved efforts. The ITPC local/regional/global structure is utilised by TMAP to initiate monitoring and advocacy to:

- · Hold country governments, multinational and bilateral organisations, and donors accountable for progress in the scale-up of HIV treatment;
- Monitor and critique challenges, accomplishments, and lessons learned in treatment delivery at the country level and make concrete recommendations for improvement to national governments, international institutions, and donors; and
- Support the growing capability of civil society as evidence-based monitors and advocates. Since its inception, TMAP has produced eight reports identifying barriers to the scale-up of quality programming and made concrete recommendations to governments and global agencies.

TMAP's Missing the Target series of reports offer a comprehensive, objective, on-the-ground analysis by civil society health consumers themselves of issues involved in the delivery of HIV services. In addition, TMAP supports its individual country teams to undertake advocacy based on country-specific research and survey findings to improve and sustain responses on the national and international levels. Since 2008, TMAP has also contributed to the delivery of HIV and health services in low- and middleincome countries by providing on-going 'south-to-south' mentoring and capacity building. In addition, TMAP's Global Fund Country Coordinating Mechanisms (CCMs) Monitoring Project assesses whether (and how) civil society representatives are able to use their positions on CCMs to have a direct impact in making Global Fund programmes more successful.

www.itpcglobal.org

### THEMATIC RESOURCES AND GUIDANCE

### **EMPOWERMENT**

- GIPA Report Card country reports (Kenya, Nigeria, Zambia, 2010) http://www.gnpplus.net/evidence/gipa-report-card/
- Global Fund to Fight AIDS, Tuberculosis and Malaria Country Coordinating Mechanisms http://www.theglobalfund.org/en/ccm/
- Global Fund to Fight AIDS, Tuberculosis and Malaria. 2010. Communities Systems Strengthening framework (May 2010) http://www.theglobalfund.org/documents/civil\_society/ CivilSociety\_CommunitySystemsStrengthening\_Framework\_es
- ► GNP+. 2011. I am one of 7 million YPLHIV advocacy messages. http://www.gnpplus.net/?s=YPLHIV+advocacy+messages
- GNP+. 2011. Brief: What is the Y+ Programme. http://www.gnpplus.net/en/resources/empowerment-of-peopleliving-with-hiv-a-their-networks/item/85-brief-what-is-the-y%20 -program
- ▶ International HIV/AIDS Alliance, GNP+. 2011. Renewing our commitment to putting GIPA into practice: Insights from the Africa Regional Programme GIPA Workshop, 6-9 December 2010, Dakar, Senegal. http://www.gnpplus.net/resources/ renewing-our-commitment-to-putting-gipa-into-practice/
- International HIV/AIDS Alliance, GNP+. 2010. Good Practice Guide: Greater Involvement of People Living with HIV (GIPA) http://www.gnpplus.net/resources/good-practice-guide-greaterinvolvement-of-people-living-with-hiv-gipa/

▶ UNAIDS. 2011. Supporting community-based responses to AIDS, tuberculosis and malaria http://www.theglobalfund.org/documents/civil society/ CivilSociety\_UNAIDSCSSGuidance\_Tool\_en/

### **HEALTH ACCESS AND PROMOTION**

- Global Fund to Fight AIDS, Tuberculosis and Malaria Pharmaceutical Procurement and Supply Management (Procurement and Supply Management; Quality Assurance Policies; Price and Quality Reporting; Procurement Support Services) http://www.theglobalfund.org/en/procurement/
- UNAIDS. 2010. Treatment 2.0 Is this the future of treatment? UNAIDS Outlook, July 2010. http://data.unaids.org/pub/ Outlook/2010/20100713\_outlook\_treatment2\_0\_en.pdf
- WHO. 2011. Adapting WHO Normative HIV Guidelines for National Programmes: Essential principles and processes (July 2011) http://www.who.int/hiv/pub/who normative/en/index.html
- WHO. 2010. Antiretroviral therapy for HIV infections in adults and adolescents: Recommendations for a public health approach (2010 Revision) http://www.who.int/hiv/pub/arv/adult2010/en/
- ▶ WHO. 2010. Antiretroviral therapy for HIV infection in infants and children: Towards Universal Access, Recommendations for a public health approach (2010 http://www.who.int/hiv/pub/paediatric/infants2010/en/
- WHO. 2010. Antiretroviral drugs for treating pregnant women and preventing HIV infection on infants: Recommendations for a public health approach (2010 Revision) http://www.who.int/hiv/pub/mtct/antiretroviral2010/en/
- WHO. 2011. Guidelines for intensified tuberculosis casefinding and isoniazid preventive therapy for people living with HIV in resource-constrained settings.

http://www.who.int/hiv/pub/tb/9789241500708/en/

- WHO. 2011. Global Health Sector Strategy on HIV/AIDS 2011-2015. http://www.who.int/hiv/pub/hiv\_strategy/en/
- WHO, UNAIDS, Deutsche Gesellschaft für Internationale Zusammenarbeit (GIZ), MSMGF, UNDP. 2011. Prevention and Treatment of HIV and other Sexually Transmitted Infections among Men who have Sex with Men and Transgender People: Recommendations for a public health approach (2011)
  - http://www.who.int/hiv/pub/guidelines/msm\_guidelines2011/ en/

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See also: resources at national level, in particular national HIV response reports, national epidemiological reports and reporting guidelines, etc.

### PLANNING AND MANAGEMENT

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