2013–
2015

People Living with HIV
Global Advocacy Agenda

Acknowledgements

We are grateful for the contributions of every person living with HIV who contributed to the LIVING 2012 consultation, which informed the development of the *People Living with HIV Global Advocacy Agenda 2013–2015*.

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Contents

Acronyms

AIDS	acquired immunodeficiency syndrome
ART	antiretroviral therapy
ARV	antiretroviral
CSO	civil society organisation
GAA	Global Advocacy Agenda
GIPA	greater involvement of people living with HIV
HIV	human immunodeficiency virus
HTC	HIV testing and counselling
IPR	intellectual property rights
LGBTI	lesbian, gay, bisexual, transgender and intersex
M&E	monitoring and evaluation
MSM	men who have sex with men
NGO	non-governmental organisation
PEP	post-exposure prophylaxis
PLHIV	people living with HIV
PreP	pre-exposure prophylaxis
PVT	prevention of vertical transmission (of HIV)
SRH/R	sexual and reproductive health/and rights
STI	sexually transmitted infection
TasP	treatment as prevention
TB	tuberculosis
UNGASS	United Nations General Assembly Special Sesssion on AIDS

This Call to Action was developed by a group of people living with HIV engaged in global advocacy work, participating in a meeting in November 2012 in Marrakech, Morocco to explore how the *Global Advocacy Agenda* could be used to support and strengthen existing advocacy efforts.

PEOPLE LIVING WITH HIV CALL TO ACTION!

Over three decades into this epidemic, we are angry that still 4,500 of us are dying of AIDS-related illnesses every day. Sixteen years after developing effective treatment, more than half of all of us who need it cannot access these life-saving drugs. The progress that has been made in treatment access is under threat.

PEOPLE WITHOUT ACCESS TO TREATMENT DIE!

We are angry that our human rights are increasingly being violated. We are faced with involuntary testing, forced sterilisation and being treated as criminals because of our HIV status. Every day we are thrown out of our homes, our schools and our workplaces.

THIS IS AN ASSAULT ON OUR HUMANITY!

We pay tribute to the women and men who started the people living with HIV movement. Because of them, we are alive today. As people living with HIV, we have achieved so much. It is people living with HIV who have:

- ➜ created harm reduction and safer sex
- ➜ inspired a whole new movement for health care
- ➜ linked health care to human rights
- ➜ brought visibility to LGBTI issues
- ➜ broken big pharma's monopoly on medicine
- ➜ brought back social and economic rights into the global conversation
- ➜ stimulated the creation of the Global Fund to Fight AIDS, Tuberculosis and Malaria.

But we are now facing more barriers to our health and our rights. We face:

- ➜ punitive laws and policies, resulting in a hostile and disabling environment
- ➜ withdrawal of funding and new trade rules and regulations, dramatically reducing our access to drugs and care
- ➜ fragmented and complacent communities, resulting in weakened advocacy.

We stand side by side as young activists living with HIV and long-term advocates to tear down these barriers.

If we don't act now, rates of new infections will rise; we will never achieve 'universal access', 'get to zero' or 'end AIDS'.

We are in a state of emergency!

We will have access to the best available prevention, treatment and care for ourselves and our children.

We will enjoy all human rights and freedoms.

We will not stand idle and watch our sisters and brothers die.

We, as a coalition of people living with HIV, unite around the *People Living with HIV Global Advocacy Agenda*, which was developed by our communities around the world. The *Global Advocacy Agenda* describes what we still need to do to ensure[i] access to prevention, treatment, care and support, to protect our human rights and strengthen all of our communities.

This is a call to reinvigorate and galvanize the people living with HIV movement in the face of this unprecedented global crisis that affects us all.

We urge all people living with HIV, networks of people living with HIV and networks of key populations, to commit to join together in solidarity.

The next struggle of the people living with HIV movement has begun. For success, we need an even greater and more forceful movement that spans every region and every country with its roots embedded deep in each of our communities.

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[i] *Positive Health, Dignity and Prevention: A Policy Framework* outlines the holistic needs of people living with HIV and all of the components required to promote the health and general well being of an individual living with HIV. The *Global Advocacy Agenda* highlights the outstanding needs, which are still to be met in order for us to enjoy our health and dignity.

PLEASE JOIN US! www.hivadvocacynow.org

Introduction

About the *People Living with HIV Global Advocacy Agenda 2013–2015*

The *Global Advocacy Agenda* (GAA) is a tool that has been used since 1999 (following the 9th International Conference for People Living with HIV in Warsaw, Poland) to articulate the advocacy issues of most importance to the community[ii] of people living with HIV (PLHIV), based on broad consultation. It has been used to guide and inform the advocacy efforts of activists, networks of people living with HIV and other organisations. It is updated and revised on a regular basis to keep up with trends and changing needs within the community.

The *People Living with HIV Global Advocacy Agenda 2013–2015* aims to guide and inform actions and programmes of networks of people living with HIV and other stakeholders through an evidence-informed advocacy strategy by and for people living with HIV. Building on the knowledge and first-hand experiences of people living with HIV is a necessary and strategic approach to take as part of efforts towards achieving the targets set out in the 2011 Political Declaration on HIV and AIDS, and the Millennium Development Goals.

The *Global Advocacy Agenda* is the document, which brings all advocacy by and for people living with HIV together and therefore is seen as a mobilising and galvanising force for the movement. The GAA was developed with three basic principles in mind.

- **We view each issue as important.** Therefore, the issues are not listed in an order of importance or priority. We are not creating a hierarchy or silos, and we refuse to allow our different issues to pit us against each other. In the context of limited resources, prioritisation all too often can pit issues, groups and needs against one another. The reality is that we are all involved in a common struggle. We recognise that it may be necessary to prioritise for strategic purposes; however, prioritisation cannot mean cutting out things that are not liked. We look for areas of agreement, and have included those in the GAA.
- **We will work towards identifying areas of consensus, and where there is no consensus, we will look for ways to identify commonalities,** such as common language and principles, including, for example: fighting against gender inequality, violence, discrimination in access services (e.g. accommodation, work, education, health care services, including psychosocial support and sexual and reproductive health (SRH), and all to be voluntary and confidential), and discrimination before the law (criminalisation, inheritance rights, consent, entry, stay and residency restrictions).
- **We will seek out and incorporate multiple viewpoints from the diversity of people living with HIV.** All these issues must be looked at through the lenses of gender, age, minority status, key population and region, so that the GAA delivers on bringing people living with HIV together. The *Global Advocacy Agenda* does not articulate how particular groups or communities should go about their advocacy work and needs to be translated for specific contexts and communities.

In the context of the *Global Advocacy Agenda*, the term key populations refers specifically to the communities of people who use drugs, sex workers,

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ii. For the purpose of this document, community is defined in its widest and most inclusive sense: a community is a group of people who have something in common and will act together in their common interest. Mostly this will be in the context of the community of people living with HIV, the group of those people who are living with HIV.

transgender people, gay men and other men who have sex with men (MSM), migrants and prisoners. The GAA acknowledges that these communities often bear multiple layers of stigma and differing challenges in claiming their rights to health and protection. These communities are mentioned explicitly when necessary to emphasise such differences.

In many contexts women and girls remain disproportionately affected by HIV and AIDS. Whilst the GAA seeks to bring all people living with HIV together, it is important that we as a community recognise and respond to such inequity in our collective agenda to realise the rights of all people.

The structure of the *People Living with HIV Global Advocacy Agenda* is based on the input from over 900 people living with HIV from all corners of the globe who participated in the e-survey, the e-consultation and the LIVING 2012 Summit. The GAA covers 16 topics, organised under 3 themes:

1. Prevention, treatment, care and support
2. Human rights
3. Community mobilisation, strengthening and activism

Each topic includes a list of advocacy points and a brief description of the main issues related to the topic. All the advocacy points call on people living with HIV to take action – either to address an issue within the community of people living with HIV itself – or to urge external stakeholders to take action.

Background

International People Living with HIV Conferences have been regularly held around the world since 1986, with the most recent being Poland, 1999, Trinidad/Tobago, 2001, Uganda, 2003, Mexico, 2008 (LIVING 2008 Summit) and and USA, 2012 (LIVING 2012). Each of these gatherings were successful in terms of bringing together hundreds of HIV-positive people from around the world in a safe and empowering environment, thus contributing to a strengthened movement of people living with HIV and advancing an evolving advocacy and action oriented strategy led by people living with HIV. Regular broad-based gatherings of people living with HIV are a vital component of the global HIV response as they build capacity, allow people to learn from and share experiences, and are a forum for strategising around global, regional and country level issues.

During the 1999 Conference in Warsaw, the community defined a *Global Advocacy Agenda* for the broad advocacy movement, which would help to shape and guide the advocacy efforts of all networks and organisations. The *Global Advocacy Agenda* has been updated on a number of occasions since 1999, the last time being in Mexico in 2008, the outcome of which formed the basis of the *Positive Health, Dignity and Prevention Framework*. The consultation process leading up to the current version of the *Global Advocacy Agenda* has been the most extensive to date.

Work leading up to the *Global Advocacy Agenda 2013–2015*

The LIVING Partnership (Box 1) made a decision to hold the *LIVING 2012: Positive Leadership Summit – the XIII International Conference of People Living with HIV* on 19–20 July 2012, immediately prior to the XIX International AIDS Conference (AIDS 2012) in Washington D.C., United States.

As a lead-up to the LIVING 2012 Summit, an extensive consultation process was undertaken. In September–December 2011, people living with HIV contributed to three separate pre-consultations, which took place in the Netherlands, the Bahamas and Ethiopia. The purpose of these meetings was to define the themes around which the LIVING 2012 consultation would be structured and the subsequent *Global Advocacy Agenda*.

Box 1: The LIVING Partnership

For their commitment to the LIVING 2012 process, gratitude is extended to the LIVING Partnership, a consortium of organisations committed to strengthening the people living with HIV movement and their communities. The partnership is currently composed of:

Global Forum on MSM and HIV (MSMGF) www.msmgf.org
Global Network of People Living with HIV (GNP+) www.gnpplus.net
International AIDS Society www.iasociety.org
International Community of Women Living with HIV/AIDS (ICW) www.icwglobal.org
International Council of AIDS Service Organizations (ICASO) www.icaso.org
International Federation of Red Cross and Red Crescent Societies www.ifrc.org
International HIV/AIDS Alliance www.aidsalliance.org
International Treatment Preparedness Coalition (ITPC) www.itpcglobal.org
Sidaction www.sidaction.org
United Nations Joint Programme on HIV/AIDS (UNAIDS) www.unaids.org
United States People Living with HIV Caucus
World Health Organization (WHO) www.who.int

The three themes of LIVING 2012 – prevention, treatment, care and support, human rights, and community mobilisation, strengthening and activism – were agreed upon in early 2012, and helped to shape the next phase of the consultation process. The consultation process took place in May and June 2012 under the umbrella of Positive Health, Dignity and Prevention (Box 2), and was designed to contribute to redefining the *Global Advocacy Agenda* for people living with HIV.

The consultation process consisted of two aspects: an e-survey followed by an in-depth e-consultation. The e-survey was held in May 2012. In total, 712 people living with HIV participated in the e-survey (Box 3), which aimed to highlight

Box 2. Positive Health, Dignity and Prevention

Positive Health, Dignity and Prevention highlights the importance of placing people living with HIV at the centre of managing their health and wellbeing. From the perspective of people living with HIV, Positive Health, Dignity and Prevention involves the following: a supportive legal and policy environment; focusing on holistic health promotion, not only on transmission prevention; tailored to setting, key populations, and to the individual; defined by people living with HIV.

As a step towards operationalising Positive Health, Dignity and Prevention, GNP+ and UNAIDS developed *Positive Health, Dignity and Prevention: A Policy Framework* (January 2011), which has five objectives. The framework recommends nine action areas (advocacy, building evidence, dissemination, policy dialogue, planning, implementation, integration, monitoring and evaluation (M&E), and adaptation and improvement) to move forward with the development of operational guidelines for positive health, dignity and prevention, with specific roles and responsibilities for GNP+, other networks of people living with HIV, civil society, the public and private sectors, UNAIDS Secretariat and cosponsors, and donor agencies.

In 2013, GNP+ and UNAIDS will release the *Positive Health, Dignity and Prevention Operational Guidelines*. These guidelines provide the suggested steps for operationalising the Positive Health, Dignity and Prevention Framework at a national level, supporting networks of people living with HIV to advocate for programming and policies, which respond to their needs in a holistic manner.

advocacy priorities for themselves and their communities from among the three themes. Based on the results of the e-survey, and in consultation with GNP+, a moderated e-consultation process, hosted by NAM[iii], was held to provide a platform for people living with HIV to participate and have their voice heard in the development of the GAA, irrespective of whether they were attending LIVING 2012 or not. The e-consultation process was held in May–June 2012.

The results of the e-survey and e-consultation were analysed and presented in three thematic papers developed to inform participants at LIVING 2012, and used to inform the development of the LIVING 2012 Summit agenda.

One hundred and ninety-nine (199) people living with HIV from 85 countries participated in the LIVING 2012 Summit. The Summit was hosted by Family Health International 360 (FHI 360) and organised by GNP+ and the LIVING Partnership. The outcomes of discussions from LIVING 2012 were presented in the LIVING 2012 Summit report (available online at: www.living2012.org/en/resources/item/131-living2012-summit-report)

A draft version of the *Global Advocacy Agenda 2013–2015* was prepared based on input from the consultation and LIVING 2012 Summit. The draft document was circulated to LIVING 2012 participants, who validated the draft GAA through an online survey. Key partners were brought together for an in-person meeting to discuss the draft GAA and how it might be used by different partners to shape their own advocacy efforts. The *Global Advocacy Agenda* was refined based on the survey and meeting results.

Therefore, the current *Global Advocacy Agenda* is based on input from hundreds of people living with HIV from around the globe and a number of key partners. This input was gathered through this series of mechanisms – the consultation, the LIVING 2012 Summit, and the validation process for the draft GAA, including the survey of LIVING 2012 participants and the Implementation Meeting.

Box 3. Consultation demographics

In total, 712 people living with HIV provided input into the e-survey and e-consultation.

- Gender: There were twice as many male as female respondents – 485 men and 220 women, and 7 transgender people.
- Age: 4.8% of participants were 15–24 years of age, 71.2% were aged 25–49 years, and 24% were 50 years of age and older.
- Length of time living with HIV (since diagnosis): 31.6% of participants reported 16 years or more, 26.7% 10–15 years, and approximately 20% less than 10 years.

There were 199 participants from 85 countries at the LIVING 2012 Summit.

- Gender: 52.3% of participants were male, 46.7% female, and 1% transgender.
- Region: North America (29.1%), Europe (26.6%), Africa (24.1%), Asia Pacific (8.5%), Latin America (7%), the Caribbean (3%), and the Middle East and North Africa (1.5%).
- Key populations: 99 individuals self-identified with a key population. They were men who have sex with men (MSM) (n=39), lesbian, gay or bisexual (n=16), people who use drugs (n=12), serodiscordant couples (n=11), young people living with HIV (n=7), religious leader (n=5), person of colour (n=3), sex worker (n=3), migrant (n=2), transgender (n=2), and former prisoner (n=1). In terms of the low number of young people living with HIV and HIV-positive faith leader attendees, both these groups had pre-conference meetings at the same time as LIVING 2012. Such a conflict was avoided with the MSM community, for whom the pre-conference was held on the day after LIVING 2012 as a result of collaboration between GNP+ and MSMGF.

iii. NAM is a community-based organisation in the UK, which delivers reliable and accurate HIV information across the world to the community of people living with HIV and other people engaged in the HIV response. NAM provided space on their online platform (www.aidsmap.com) for the LIVING Partnership to conduct the e-discussions in 2012.

Guiding principles

- The *Global Advocacy Agenda* emphasizes that only through a rights-based approach to the HIV response, which focuses on social justice, can positive public health outcomes be achieved. People living with HIV strive for policies and programmes that do not oppress, manage, control abuse or criminalise them. Such policies and programmes must enable people living with HIV to protect themselves and others – not through fear but through empowerment, and with dignity.[iv]
- The *Global Advocacy Agenda* theme of community mobilisation, strengthening and activism underpins the achievement of the specific needs outlined under the human rights and prevention, treatment, care and support themes and the entire HIV response. To achieve these objectives, the community of people living with HIV requires adequate resources and the appropriate capacity to conduct effective advocacy, mobilise their peers to increase access to services, provide services and interventions, and hold their governments accountable.
- People living with HIV have a great deal of knowledge, experience and insight into the issues that are important to them and for responding to the epidemic effectively. If the health, dignity and prevention needs of people living with HIV are to be adequately addressed, they must be meaningfully involved in all aspects of policies and programmes that impact them.[v]
- The HIV epidemic disproportionately affects women and girls. The people living with HIV advocacy community must make concerted efforts to ensure the greater and more meaningful engagement of women living with HIV in the policy dialogues and leadership roles that influence their health and well-being.
- The continued growth and development of the community of people living with HIV is dependent on effective leadership renewal strategies. These strategies must acknowledge the skills and capacity of young people living with HIV, the expertise and experience of other leaders, and the appropriate and meaningful mentorship and support for new emerging leaders.
- The *Global Advocacy Agenda* recognises that the needs of an individual living with HIV must be addressed holistically, placing HIV in the context of other health needs as they develop. Where appropriate, the integration of HIV services within other settings – such as TB treatment and care services, harm reduction[vi] and sexual and reproductive health services – can increase access and acceptability for particular groups.
- While the *Global Advocacy Agenda* is led by the community of people living with HIV, we recognize the critical role of partners, including UN agencies, civil society, donors, governments and other social justice movements in achieving our objectives as laid out in the *Global Advocacy Agenda*. We acknowledge the need to look outside our sector and work collaboratively with non-traditional partners to achieve common objectives.
- The community of people living with HIV is extremely diverse. While we are united by a common mission, we do not hold any one 'identity'. The *Global Advocacy Agenda* respects that diversity. Our common advocacy aims are strengthened through a recognition and respect for the different perspectives, experiences and challenges faced by positive community. The *Global Advocacy Agenda* draws on these strengths.

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iv. This guiding principle has been adapted from *Positive Health, Dignity and Prevention: A Policy Framework*. GNP+, UNAIDS. 2011.

v. ibid

vi. Harm reduction in this context refers to a range of services, which should include syringe exchange programmes (SEPs) and opioid substitution therapy (OST).

Prevention, treatment, care and support

Although these topics are presented separately, many are inter-related. For example, appropriate linkages between testing, diagnostics and monitoring, treatment literacy, psychosocial support and access to antiretroviral (ARV) drugs ensure that people living with HIV are retained in and have access to quality services.

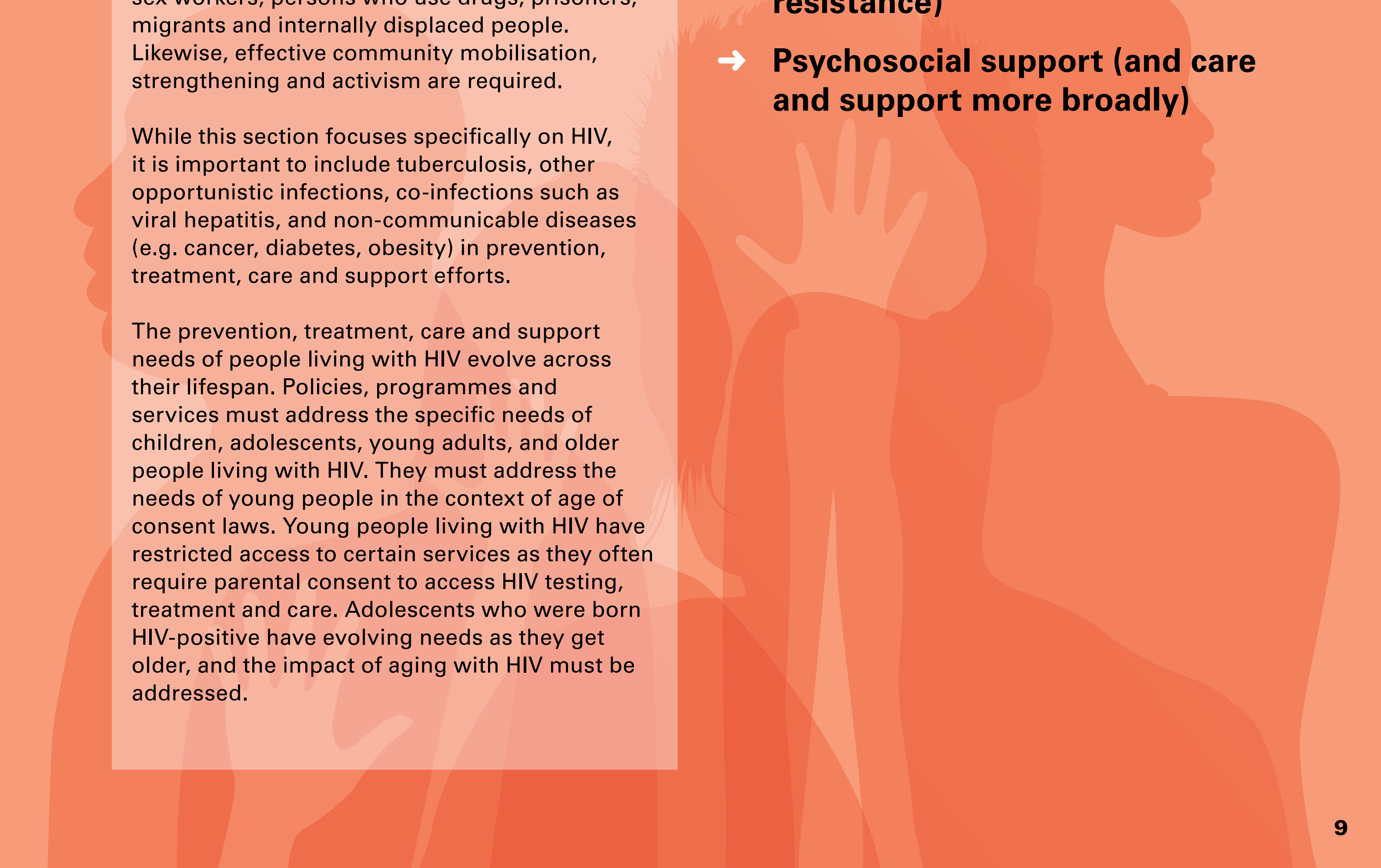
It is important to recognise that prevention, treatment, care and support are closely linked to human rights, community mobilisation, strengthening and activism, which are discussed in other sections. Indeed, access to prevention, treatment, care and support require rights-based approaches, and will not be achieved without addressing the human rights contexts of HIV, especially for women and girls, young people, and key populations such as transgender people, gay men and other men who have sex with men, sex workers, persons who use drugs, prisoners, migrants and internally displaced people. Likewise, effective community mobilisation, strengthening and activism are required.

While this section focuses specifically on HIV, it is important to include tuberculosis, other opportunistic infections, co-infections such as viral hepatitis, and non-communicable diseases (e.g. cancer, diabetes, obesity) in prevention, treatment, care and support efforts.

The prevention, treatment, care and support needs of people living with HIV evolve across their lifespan. Policies, programmes and services must address the specific needs of children, adolescents, young adults, and older people living with HIV. They must address the needs of young people in the context of age of consent laws. Young people living with HIV have restricted access to certain services as they often require parental consent to access HIV testing, treatment and care. Adolescents who were born HIV-positive have evolving needs as they get older, and the impact of aging with HIV must be addressed.

This section includes seven topics:

- ➜ **Increasing access to antiretroviral drugs for all those who need them**
- ➜ **Prevention of vertical transmission**
- ➜ **Treatment as prevention**
- ➜ **HIV testing and counselling**
- ➜ **Treatment literacy**
- ➜ **Diagnostics and monitoring (viral load, CD4 count and drug resistance)**
- ➜ **Psychosocial support (and care and support more broadly)**



Increasing access to antiretroviral drugs for all those who need them

> “We as a community need to forge greater partnership with other communities to apply pressure on governments to ensure equal access to treatment and care in a holistic manner.”
>
> E-CONSULTATION PARTICIPANT

People living with HIV advocate for…

- ➜ Reliable and sustainable access to the highest quality medicines, diagnostics and monitoring for all people living with HIV, including access to second- and third-line treatment regimens.
- ➜ Strengthened health systems providing client-centered services to ensure universal access; training and sensitisation of health care workers to reduce stigma and discrimination;
- ➜ Treatment for TB and other opportunistic infections, co-infections such as viral hepatitis, and non-communicable diseases (e.g. cancer, diabetes); care for the needs of children, adolescents, young people and older people living and aging with HIV; decentralised ART services; and, high quality, on-going training for people living with HIV to deliver community-based services.
- ➜ Regularly updated treatment guidelines.
- ➜ Increased, sustainable and predictable funding for treatment, prevention, care and support programmes and services, including from domestic sources.
- ➜ Trade agreements and intellectual property rights (IPR) that work in the public interest and allow countries to purchase generic drugs, to ensure that drugs are affordable and available to all that need them.
- ➜ The removal of all legal barriers and policies which hinder access to treatment for all, including those that affect women and young people, as well as those that specifically affect populations such as migrants, internally displaced people, people who use drugs, sex workers, prisoners, and gay men and other men who have sex with men.
- ➜ Increased, long term capacity-building to strengthen the leadership of people living with HIV in efforts to achieve universal access to ART and to make informed decisions around their care.
- ➜ Treatment literacy programmes that support the right of people living with HIV to choose when to start treatment.
- ➜ Rights-based policies and approaches to treatment as prevention and prevention of vertical transmission that recognise that ART is primarily for the health of people living with HIV, and the rights of all people to decide whether and when to start ART.

What are the main issues?

The availability of ART and related services does not mean that they are accessible. Treatment access requires that services include the 3 ‘A’s: Available, Accessible and Affordable for everyone.

Many factors influence treatment access, including: the state of health systems and levels of funding; drug prices, the impact of trade agreements, and the availability of diagnostics monitoring, and drugs, including generics; treatment guidelines and treatment literacy programmes; a robust, mobilised community that demands access to treatment; stigma and discrimination in healthcare settings, legal barriers, and respect for human rights; and, the way in which treatment-related programmes are implemented.

Treatment access is highly dependent on the strength of health systems and the state of access to health services in urban, rural and remote areas. This requires sustainable funding from both international and domestic sources. Cost-effectiveness arguments have been used to convince funders and policy-makers to increase access to ART, and are often very useful. However, advocacy messaging must acknowledge that access to treatment to all who need it is first and foremost about the right to health and the right to life.

Intellectual property rights, drug and commodity prices, trade agreements, and the ability of countries to purchase generic drugs all affect access to drugs. There are also concerns about the cost to patients, treatment regimes, expiration, toxicity, quality and stock outs of drugs. Diagnostics-related issues include access to regular blood tests, adherence and monitoring.

Treatment access is influenced by the existence and implementation of regularly updated treatment guidelines. Availability of second- and third-line therapies helps ensure that people living with HIV have access to appropriate treatment regimens. Treatment literacy helps ensure retention regarding care and increases knowledge of people’s right to health, including equitable access to treatment and care, and the right to confidentiality and privacy.

Stigma and discrimination in health care settings hinder access to those who need ARV medication and other treatment services. The legal barriers, criminalisation and marginalisation faced by some populations, such as migrants, internally displaced people, people who use drugs, sex workers, prisoners and gay men and other men who have sex with men, mean that they may not be reached by services. Respect for the voluntary and informed choice of when to start ART is a human right.

In the context of treatment as prevention (TasP), there is a need to prioritise people who need treatment to survive, and to consider the ethics of putting people on treatment for prevention purposes when they do not require it for their own personal health, including pregnant women and people living with HIV from key populations.

> “We … commit to accelerate efforts to achieve the goal of universal access to antiretroviral treatment for those eligible based on World Health Organization HIV treatment guidelines … with the target of working towards having 15 million people living with HIV on antiretroviral treatment by 2015.”
>
> 2011 UN POLITICAL DECLARATION ON HIV AND AIDS

Prevention of vertical transmission

People living with HIV advocate for…

- Scale up of prevention of vertical transmission (PVT) availability, access and coverage, and greater integration within broader health care systems.
- Scale up of HIV testing and counselling for pregnant women.
- Access to highest quality ARVs for mothers and children.
- Universal and rapid phase-out of single dose nevirapine in PVT programmes.
- Application of international guidelines at national and institutional levels, done in a way that will not compromise access options for women living with HIV.
- Education and empowerment for women to learn about their sexual and reproductive rights and how to protect these rights.
- Respect by healthcare workers, families, and community members for women’s sexual and reproductive health and rights (SRHR), including the right of women living with HIV to have a child. The right of men living with HIV to have children must be respected.

> “We … commit to working towards the elimination of mother-to-child transmission of HIV and substantially reducing AIDS-related maternal deaths by 2015.”
>
> 2011 UN POLITICAL DECLARATION ON HIV AND AIDS

- An immediate and universal end to forced abortions and sterilisation of women living with HIV.
- Enhanced and continuing PVT training for health care providers.
- The inclusion of men in PVT programming where and when appropriate.

What are the main issues?

> “We, as advocates working at the grassroots level should also spread the message of early testing to mothers and ensure that they go for their follow up to enable the required treatment and care to prevent infection of their babies”.
>
> CONSULTATION PARTICIPANT

There has been an increase in the availability of prevention of vertical transmission services over the last decade, although the level of availability, access and coverage varies in each country and between regions.

Some of this is due to a lack of access to general health services – access to PVT means that first there has to be access to health services. Many women do not have access to basic health services, and have late access to antenatal care. There is also a lack of PVT integration between HIV services and other health services, such as family planning and maternal-child health.

As a point of access to care, there has to be an increased offer of HIV testing and counselling (HTC) among pregnant women, and follow-up for PVT. However, testing has to be a voluntary choice and must ensure confidentiality. Also, it is necessary to examine whether HIV testing is a precondition to access other services and work to end this practice where it is found to exist.

Misinformed health workers lead to misinformed health decisions. We must move beyond providing healthcare workers with short one-time PVT training, especially as there is a relatively swift turnover rate of local health care workers, particularly in developing countries.

PVT treatment guidelines are not applied consistently and include contradicting messages. Health institution policies should be updated on a regular basis based on national guidelines. WHO guidelines can be used as an entry point for regularly reviewing and monitoring national guidelines. Treatment for mothers and children must be considered, including access to ART and the removal of single dose nevirapine. A rights-based approach must always be used. There are concerns that the implementation of WHO’s prevention of vertical transmission guidelines will compromise access to options for women living with HIV.

Women must be at the centre of the services. The empowerment of women living with HIV will help ensure their involvement in decision-making. Many women are told that they should be sterilised in order to prevent pregnancy. We must dispel misinformation and defeat any attempts at forced or coerced abortion and sterilisation of HIV-positive women. We must uphold women’s sexual and reproductive health and rights, including prevention of unintended pregnancy and the right to have a child. Strategies for the appropriate involvement of men should also be considered. Documenting stories of HIV-positive women having healthy births could help address misconceptions.

There is a need to address the social determinants of health; PVT happens in a context of religion, poverty, culture, economic status, laws, violence against women, etc. This requires forming systemic linkages between PVT and human rights-based social protection services, including after birth, and in particular for HIV-positive sex workers and people who use drugs (social protection, right to custody, etc.).

Treatment as prevention

People living with HIV advocate for…

- ➜ Access to treatment for all people living with HIV who need it for the benefit of increasing the quality and length of life.
- ➜ The full involvement of people living with HIV in the development of treatment as prevention (TasP[vii]) strategies and implementation processes.
- ➜ A rights-based approach to TasP that respects the human rights of people living with HIV.
- ➜ Dissemination and provision of accurate information on treatment and TasP to support informed and voluntary decisions around treatment initiation for people living with HIV.
- ➜ Education, awareness and capacity-building for key stakeholders (people living with HIV, treatment activists, policy-makers) on various approaches to TasP.
- ➜ Opportunities to leverage TasP as a beneficial public health investment and cost saving measure to further advocate for increased treatment access for all those who need it.
- ➜ Combination prevention, which includes TasP and other ARV-based biomedical prevention technologies.
- ➜ Development and implementation of a robust TasP research agenda examining issues such as the optimal time to start treatment, benefits, side effects and toxicity for various communities of people living with HIV (based on age, gender, viral load levels, CD4 counts, serodiscordant relationships status), and adherence.

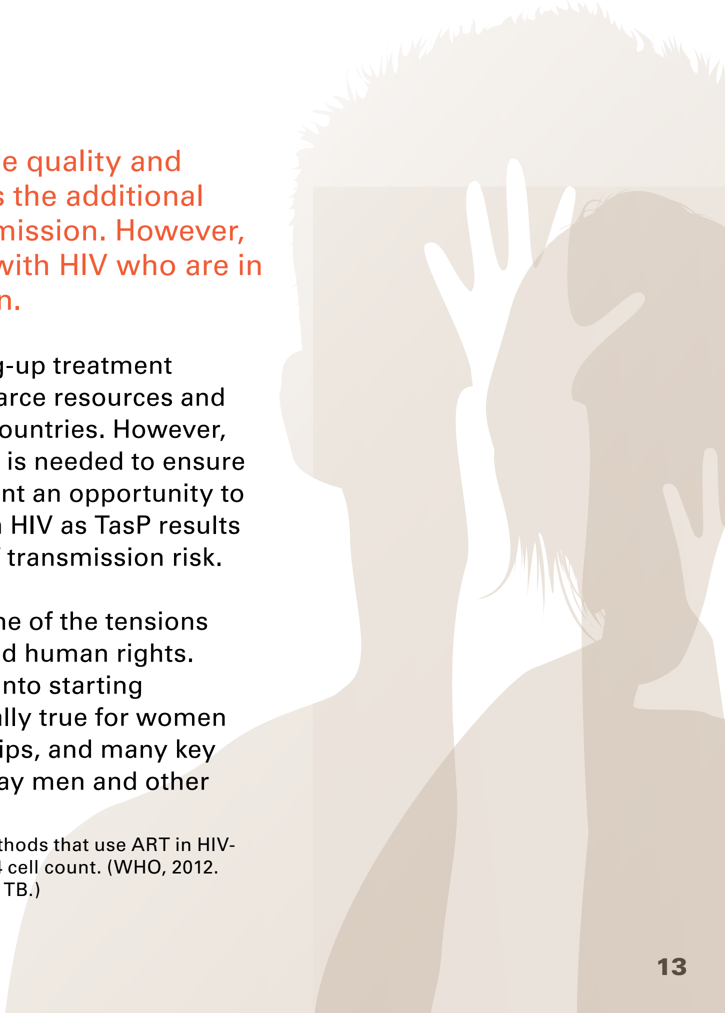
> “People living with HIV networks, and advocates working on behalf of HIV-positive people, should take ownership of the ‘treatment as prevention’ agenda to ensure that ART is primarily for the health needs of HIV-positive people and that the prevention benefits are seen as an important secondary goal.”
>
> GNP+ (2010). ‘THE ROLE OF PEOPLE LIVING WITH HIV IN NEW PREVENTION TECHNOLOGIES: OUR ADVOCACY AGENDA’.

What are the main issues?

Treatment is primarily for the benefit of increasing the quality and length of life of people living with HIV. Treatment has the additional benefit of significantly reducing the risk of HIV transmission. However, ensuring that treatment is available to people living with HIV who are in need takes precedence over using ART for prevention.

TasP has the potential to provide new momentum for scaling-up treatment access for people living with HIV, against the backdrop of scarce resources and an uncertain economic climate among donor and recipient countries. However, TasP does not replace community interventions and funding is needed to ensure access to other proven prevention methods. TasP may present an opportunity to reduce stigma and discrimination towards people living with HIV as TasP results in a very significant reduction – some say an eradication – of transmission risk.

TasP raises important ethical and human rights concerns. One of the tensions frequently mentioned is between public health objectives and human rights. There is concern that people living with HIV will be coerced into starting treatment for the public health benefits. This may be especially true for women and girls, young people, people in serodiscordant relationships, and many key populations such as sex workers, transgender people, and gay men and other



[vii] Treatment as prevention (TasP) is a term used to describe HIV prevention methods that use ART in HIV-positive persons to decrease the chance of HIV transmission independent of CD4 cell count. (WHO, 2012. Programmatic Update – Antiretroviral Treatment as Prevention (TasP) of HIV and TB.)

men who have sex with men. Individuals must be provided with all available information on the benefits and risks of starting treatment for their own health, including any gaps in knowledge concerning the best time to start treatment. Related concerns include levels of adherence support and treatment literacy, toxicity and side effects, and a stable supply of ART.

There are gaps in knowledge related to treatment and TasP, including: optimal time to start treatment; toxicities and side effects of TasP for all age groups, as well as on gender- and economic-related issues; affordability and cost effectiveness; drug resistance; and, benefit and risks for people living with HIV that have higher CD4 cell counts. Advocacy should be based on available evidence. This requires that knowledge gaps be addressed. A robust research agenda must be supported to answer these questions.

The concept of TasP is unclear and not well understood by the HIV community. Communities of people living with HIV must first learn about study results and what it means to them. There is often some confusion between various approaches to TasP, as well as between TasP and pre-exposure prophylaxis (PrEP) for HIV-negative members of key populations. People living with HIV, treatment activists, and policy-makers need much more information about TasP. Discussions need to start at the grassroots level to determine the best approach to implementing TasP so as to attain the principal goal of equal rights to health for everyone.

> “We have to base our information on evidence. Then let us start advocating with those figures or influential community parts. PLHIV have to advocate for [TasP] because the objective of the struggle of PLHIV is to save other people. So we have to stand in front as usual.”
>
> CONSULTATION PARTICIPANT

HIV testing and counselling

People living with HIV advocate for…

- The development of rights-based policies and services that appropriately and adequately address the needs of women, couples, children, young people and key populations.
- Development and scale up of HIV testing and counselling (HTC) services in ‘safe’ settings, where those seeking HTC can be assured of anonymity and confidentiality – particularly for women and key populations.
- Rights-based approaches to HTC and linkages to care and treatment that respect the right to confidentiality, and the right to voluntary testing and treatment.
- Rapid scale up of testing for couples within HTC programmes, and in the case of heterosexual couples, using the opportunity to address gender-related challenges to disclosure.
- An immediate end to compulsory testing on HIV and sexually transmitted infections (STI) for sex workers.
- Increased and sustained funding for HTC services.
- Regular review and adoption of guidelines and standards on HTC.
- Scale-up of capacity development for counsellors and testers.
- Comprehensive counselling support for people living with HIV at various entry points within healthcare settings.
- Initiatives that increase demand for testing from the community.

> “We … commit to redouble HIV prevention efforts by taking all measures to implement comprehensive, evidence-based prevention approaches, including through … significantly expanding and promoting voluntary and confidential HIV testing and counselling and provider-initiated HIV testing and counselling …”
>
> 2011 POLITICAL DECLARATION ON HIV AND AIDS

What are the main issues?

HIV testing and counselling is a critical entry point into prevention, treatment, care and support services for people living with HIV. A strong link exists between increased HTC (coverage and quality) and treatment access.

The availability of HTC has increased in some countries, though service quality and accessibility varies. There are a number of challenges, including barriers to access for children and young people (age of consent laws) and key populations, as well as issues of confidentiality (particularly for key populations), funding, and the use of non-rights-based approaches to HTC. For example, sex workers are sometimes forced to undergo HIV and STI testing. Countries need to review policies in relation to parental consent for HTC among children and young people. For the general population HTC is readily accessible, though for key populations it is not. With funding cuts it is uncertain how many HTC services will survive.

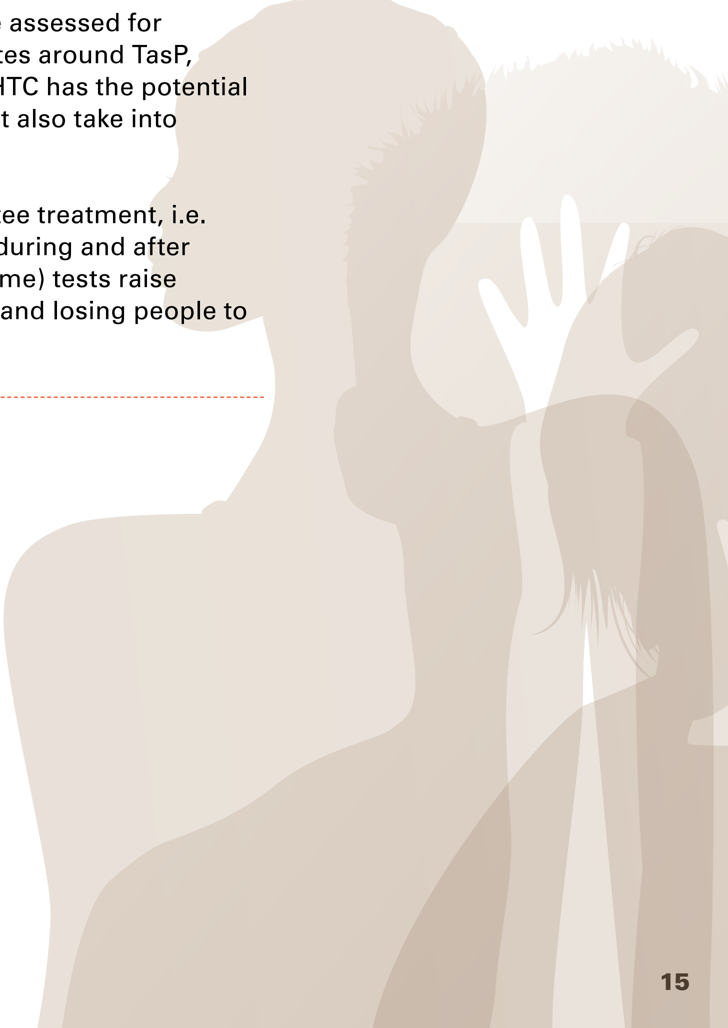
People are often more comfortable accessing HTC in their communities, rather than in government or outside health facilities. Therefore, community involvement is an essential factor to ensure HTC coverage and quality. However, there is also recognition of the need to normalise testing, e.g. testing at primary healthcare clinics and not only in HIV-specific clinics or centres of care. HTC must be accessible in non-stigmatising environments, and there is a need to focus on HTC for key populations. This requires revised normative guidance and ensuring the quality of counsellors and testers.

Pre- and post-test counselling is required for everyone. There must be respect for confidentiality, the right to full information, and the use of non-discriminatory and easy to understand language. Furthermore, there may be opportunities to reach people with low literacy levels in particular through the use of new communication technologies.

Where TasP programmes are being implemented, HTC provides an excellent opportunity to identify serodiscordant couples that could be assessed for initiation of TasP (or PrEP). However, given the current debates around TasP, there is a fear of possible coercion into treatment. Couples HTC has the potential to address the gender challenges of disclosure, but this must also take into consideration safeguards for the individuals.

There are concerns with HTC campaigns that do not guarantee treatment, i.e. testing for testing's sake, without proper linkages with care during and after testing. This is a health systems issue. Over-the-counter (home) tests raise similar concerns around the risks of inadequate counselling and losing people to care compared to point-of-care testing.

> “I was scared for a long time to get a [HIV] test, but when a new testing centre opened just for young people I felt safe to go there alone, I was diagnosed HIV-positive and have been attending a post test club ever since. The friends and support I get there has given me much more self confidence.”
>
> CONSULTATION PARTICIPANT



Treatment literacy

> “When I found out I was pregnant I was really afraid that my [HIV] medication would harm my baby. My doctor took the time to explain my options to keep my baby and me both safe. Together we made the decision to switch medication for my pregnancy. My son is now one year old and we are both very healthy.”
>
> CONSULTATION PARTICIPANT

People living with HIV advocate for…

- The inclusion of, and adequate funding for, treatment literacy in all national HIV programmes.
- Urgent scale up of treatment literacy programmes that address the specific needs of women, young people, serodiscordant couples, and key populations such as people who use drugs and transgender people among others.
- A strategic approach to treatment literacy that takes into account the various type of treatment literacy required according to the target audience and their needs (people living with HIV, healthcare providers, policy-makers, advocates).
- Treatment literacy programmes that address TB, other opportunistic infections, co-infections such as viral hepatitis, and non-communicable diseases (e.g. cancer, diabetes, obesity), and that address the needs of children, adolescents, young people and older people living and aging with HIV.
- Increased recognition of people living with HIV as experts on issues related to HIV and treatments and their inclusion in all aspects of treatment literacy programme development and implementation.
- Increased, regular and up to date training on treatment for health care providers.
- The development of standardised treatment literacy training and information, regularly reviewed to reflect changes in treatment.

What are the main issues?

People living with HIV who are treatment literate become empowered to make informed decisions. Treatment literacy can increase treatment access, adherence and the quality of individuals’ lives. It contributes to positive public health outcomes. It has also been known to increase the involvement of people living with HIV in service delivery and advocacy for better quality services.

Treatment literacy programmes also provide an entry point for empowerment of communities to demand accountability from their leaders and governments in terms of treatment affordability, accessibility and appropriateness of delivery (including human rights and legal issues associated with key populations, stigmatisation in health care settings, etc).

However, treatment literacy is often not included in national HIV responses. Also, treatment is not always available after providing people living with HIV with treatment literacy programmes. In addition, treatment literacy is often seen as the ‘unfunded mandate’ of community groups. People living with HIV are often not recognised as experts in treatment literacy.

There is a need to strengthen and formalise relationships between healthcare providers and community groups, especially when reaching out to key populations. Treatment literacy programmes should be designed to address the needs of women, young people, serodiscordant couples, and key populations. They should take into account co-infections such as TB and viral hepatitis.

Different populations have different needs when it comes to understanding treatment, and general treatment literacy modules will not suffice. For example, people who use drugs will want to know more about drug interactions between heroin and other drugs, opioid substitution therapy (OST) and ARVs. Likewise, treatment literacy programmes need to be able to support serodiscordant couples to understand what the evidence says, to know how to access and understand their current serological condition (including CD4, viral load, other STIs), and to be able to make decisions based on accurate information. Transgender people need information on the interaction between ART and hormone therapy.

A strategic approach to treatment literacy is needed. The type of treatment literacy required varies according to the target audience and their needs: people living with HIV to manage their own health; healthcare providers to do their jobs well (including non-HIV specialists); policy-makers to make decisions about treatment programmes; advocates to be effective in their efforts.

It would be useful to have standardised treatment literacy modules endorsed by UN agencies, and globally centralised information on treatment literacy for quality assurance. Furthermore, new information around treatment, laws, and research findings should also form part of treatment literacy. This often requires complementary expertise in different technical areas (e.g. human rights, IP, citizenship, etc.).

Diagnostics and monitoring (viral load, CD4 count and drug resistance)

> “We … commit to remove before 2015, where feasible, obstacles that limit the capacity of low- and middle-income countries to provide affordable and effective HIV prevention and treatment products, diagnostics, medicines and commodities and other pharmaceutical products …”
>
> 2011 POLITICAL DECLARATION ON HIV AND AIDS

People living with HIV advocate for…

- Increased availability, access and funding for diagnostic technologies and services.
- Reduced prices for diagnostic technologies and reagents as well as reduced cost to end users (e.g. increased insurance coverage), and simplified equipment (e.g. through competition and incentives).
- Meaningful participation of people living with HIV in the development of guidelines on diagnostics (e.g. WHO).
- Strengthened community knowledge and understanding on the importance of viral load, CD4 count and drug resistance testing.
- Increased assessment and research on the cost effectiveness of diagnostic services to build evidence and justify the need for rapid scale up of these services.
- Development of strong alliances with national stakeholders to advocate for and ensure adequate funding for diagnostic technologies and services within domestic health budgets and in health systems strengthening.

What are the main issues?

Viral load, CD4 and drug resistance tests are useful for the purposes of medical monitoring by doctors, but also constitute an essential tool for people living with HIV to monitor their own health. In the event of prioritisation, viral load and drug resistance testing are more essential than CD4 tests in monitoring treatment effectiveness and its relevance to public health considerations.

> “PLHIV need to be sensitised about the importance of the two tests, I personally didn’t know that viral load is important until I talked to my friends in other countries who have these services.”
>
> CONSULTATION PARTICIPANT

> “PLHIV need to raise their voice and do a lot of advocacy inside of their country to make government understand that those [diagnostics] need to be provided ... In our country ... viral load wasn’t done for more than 18 months but PLHIV raised their voice ... and when the media found out about the problem, they [criticised] the ministry of health... and after that the tests were provided in less than a month ... So raising our voice is the main weapon in the battle for providing necessary tests and drugs.”
>
> CONSULTATION PARTICIPANT FROM MACEDONIA

The cost of diagnostic equipment and materials places a significant burden on middle- and low-income countries. Without creating significant dependency on donor’s intervention, it is almost impossible for many governments to allocate health budgets to cover the costs of all diagnostic services. As a result, the number of diagnostic testing facilities is limited, thus sacrificing quality of care. Further, diagnostic facilities are generally located in capital cities with long waiting lists, resulting in significant delay in receiving results. This centralisation of facilities can also result in increased indirect health expenses for people living with HIV in rural areas due to travelling time and distance. Even where satellite sites have been established, these often involve considerable distance and transportation costs. Other issues include stock-outs, lack of service integration, the need for community educators, and a lack of clarity on which guidelines to use.

Increasing treatment literacy also means sensitising community and activist groups to the need for improved diagnostic policies and increased resources. Partnerships among civil society organisations (CSOs) are needed to coordinate advocacy efforts and messages. Greater collaboration and linkages between self-help groups and healthcare workers should be formalised through, for example, developing working protocols and supporting self-help groups to provide treatment literacy and peer education. This includes increasing community knowledge of CD4 count, and interpretation of viral load and drug resistance test results. People living with HIV should also participate in WHO consultations as guidelines on diagnostics are developed.

Psychosocial support (and care and support more broadly)

People living with HIV advocate for...

- Prioritisation of adequate resourcing for psychosocial support services within national HIV responses.
- Psychosocial support systems and programmes which act to empower people living with HIV to determine and manage their own health care.
- Programmes and services that address HIV-specific and related psychosocial, care and support needs of people living with HIV including those from key populations – mental health programmes, harm reduction services, nutritional support, housing programmes, home-based care, and palliative care.
- Social protection policies and programmes, including those that support a livelihood for people living with HIV.
- Increased capacity development for, and investment in, community workers to provide psychosocial support services.
- Standards and guidelines for non-governmental organisation (NGO) social workers to ensure equal recognition with medical professionals.
- Standards and guidelines for linking clinical and community support services, as well as other related services such as mental health programmes, harm reduction services and housing.
- Task shifting to and increased investment in community systems in order to maximise cost effectiveness in care and support, and ensure such care and support is located within community support.
- Increased research and evidence (and funding for research) examining the benefits of psychosocial support, and successful models.
- Strengthened strategic partnerships with support services for other communicable diseases (TB, viral hepatitis) and non-communicable diseases (cancer, diabetes, obesity).

What are the main issues?

Psychosocial support increases the quality of life of people living with HIV. It enables them to be mentally and physically fit to manage their health (including support treatment adherence) and to deal with socioeconomic factors and life events.

There is a lack of programmes focusing on emotional, spiritual and social support for people living with HIV to effectively deal with personal and family issues. Psychosocial support should be provided through a more comprehensive and well-designed process.

In general, psychosocial support has received a low priority in many national HIV responses, with NGOs and CSOs attempting to fill the gaps. Some of the gaps are often health systems-related, including a lack of human resources, lack of funding, lack of well-designed programmes, and lack of coordination and integration of psychosocial services with other programmes.

A broad range of psychosocial, care and support programmes and services are needed that are both HIV-specific and that address related issues, including for key populations. This includes mental health programmes, harm reduction services, nutritional support, housing programmes, home-based care, palliative care, and social protection programmes.

A holistic approach should be supported through the *Positive Health, Dignity and Prevention Framework*, whereby a patient-centred care approach is used in which HIV-positive people are active agents in healthcare, not just passive recipients. Furthermore, people living with HIV can be involved as paid peer counsellors and supporters in peer support programmes to provide treatment literacy, psychosocial support and to develop new leadership. This requires investment in training and specialisation. In addition, HIV-positive people can be accountable for funding for psychosocial support and monitor its inclusion in the continuum of care.

> “It is really hard to go to collect my ARVs as they judge me for using drugs. It would be so much easier if I were able to get treatment for HIV in the same place that I access my OST, where I can get the support I need from peers and others who understand my needs”.
>
> CONSULTATION PARTICIPANT

Human rights

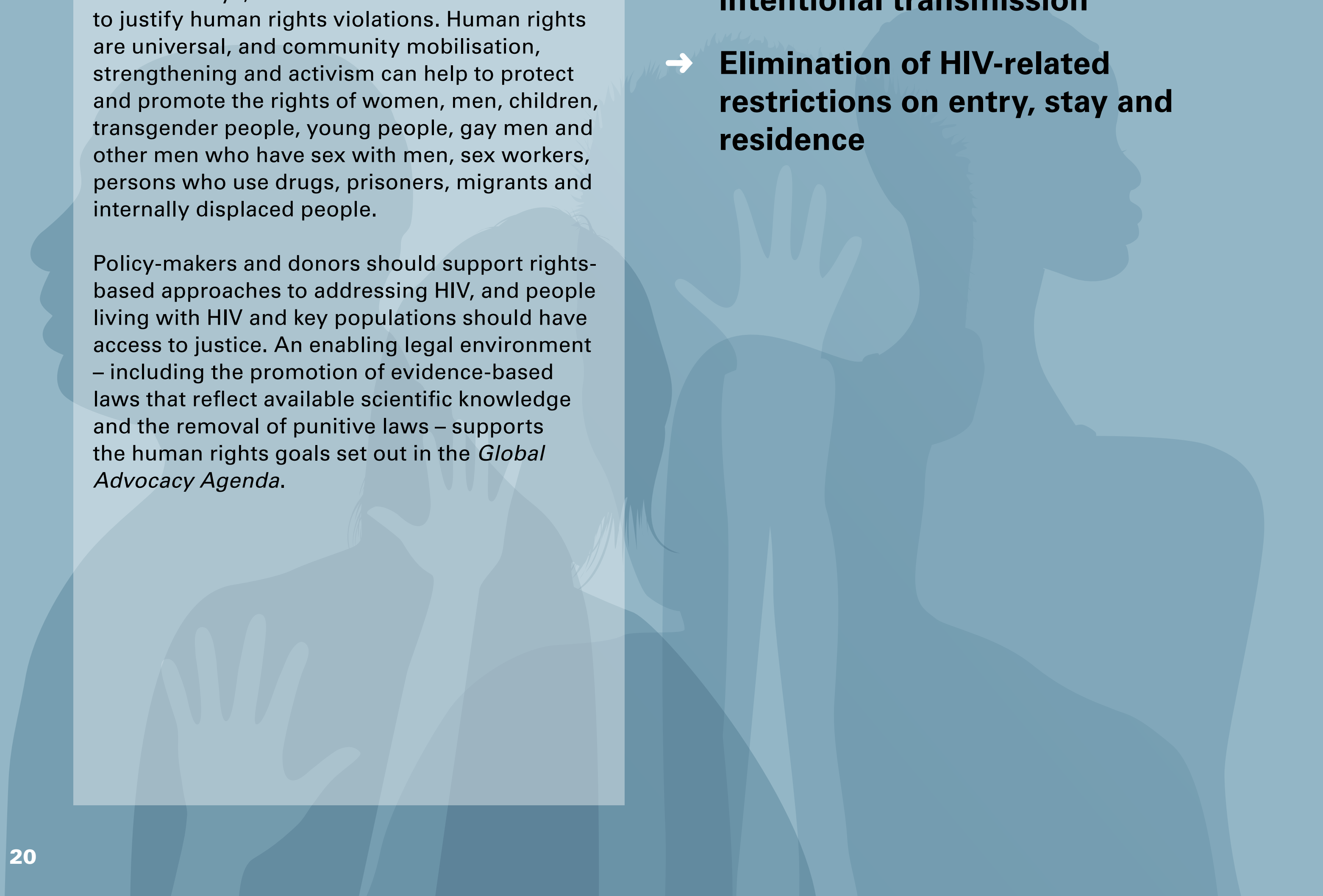
Although these topics are presented separately, many are inter-related. For example, stigma and discrimination are important barriers to the realisation of sexual and reproductive health and rights, and they fuel criminalisation and restrictions on entry, stay and residence.

It is important to recognise that human rights are closely linked to prevention, treatment, care and support, as well as to community mobilisation, strengthening and activism, which are discussed in other sections. Indeed, rights-based approaches are required for all topics discussed in the section on prevention, treatment, care and support. Human rights can be promoted and protected in culturally sensitive ways, and culture should not be used to justify human rights violations. Human rights are universal, and community mobilisation, strengthening and activism can help to protect and promote the rights of women, men, children, transgender people, young people, gay men and other men who have sex with men, sex workers, persons who use drugs, prisoners, migrants and internally displaced people.

Policy-makers and donors should support rights-based approaches to addressing HIV, and people living with HIV and key populations should have access to justice. An enabling legal environment – including the promotion of evidence-based laws that reflect available scientific knowledge and the removal of punitive laws – supports the human rights goals set out in the *Global Advocacy Agenda*.

This section includes four topics:

- ➜ **Eradicating stigma and discrimination (and protecting the right to confidentiality and privacy)**
- ➜ **Sexual and reproductive health and rights**
- ➜ **Ending criminalisation of HIV non-disclosure, potential or perceived exposure, or non-intentional transmission**
- ➜ **Elimination of HIV-related restrictions on entry, stay and residence**



Eradicating stigma and discrimination (and protecting the right to confidentiality and privacy)

People living with HIV advocate for…

- ➜ The introduction, enforcement, and resourcing of anti-discrimination laws in all countries.
- ➜ An end to discriminatory policies and requirements in employment, education, marriage, insurance, bank loans, travel and immigration.
- ➜ An end to policies and laws that present a barrier to access to services for people living with HIV, including women and girls, transgender people, young people, sex workers, persons who use drugs, gay men and other men who have sex with men, migrants, internally displaced people, and prisoners.
- ➜ Policies, programmes and services that address the multiple layers of stigma and discrimination that confront people living with HIV from key populations, and that address self-stigma and support people living with HIV to become more resilient.
- ➜ Action by governments, non-governmental institutions and individuals where there is a clear violation of the right to confidentiality of people living with HIV.
- ➜ Broader community leadership in the support of human rights, including the rights of people living with HIV.
- ➜ An end to gender based violence against women, lesbians and other women who have sex with women, gay men and other men who have sex with men, transgender people, sex workers and all young people.
- ➜ The implementation of evidence-gathering tools (e.g. the *People Living with HIV Stigma Index*) to gather facts and inform strategies to address stigma and discrimination.
- ➜ Campaigns and education programmes on HIV, stigma and discrimination, in schools and in the workplace to address myths and fears. This includes risk literacy to address the misconceptions about the risks of HIV transmission.
- ➜ The integration of HIV-related stigma and discrimination curricula into health care worker pre- and in-service training.
- ➜ Accountable health systems and health care workers, sensitive to gender, age, and HIV-status, and where confidentiality is guaranteed.
- ➜ Long term support and services for people living with HIV so that they can make voluntary and informed decisions on whether to disclose their HIV status.
- ➜ An end to stigma in faith settings through programmes to sensitise faith-based groups and leaders to counter discrimination, and homophobia, as an impact of fundamentalism and religious dogma.

What are the main issues?

Stigma and discrimination in health care settings, the workplace, the community, and in faith settings, as well as violations of confidentiality and privacy, are critical issues for the protection of the human rights of people living with HIV.

> “We … commit to intensify national efforts to create enabling legal, social and policy frameworks … in order to eliminate stigma, discrimination and violence related to HIV and promote access to HIV prevention, treatment, care and support and non-discriminatory access to education, health care, employment and social services, provide legal protections for people affected by HIV, including … respect for privacy and confidentiality … with particular attention to all people vulnerable to and affected by HIV.”
>
> 2011 POLITICAL DECLARATION ON HIV AND AIDS

> “Healthcare providers are sometimes the only people who know our diagnosis, which can put us in a vulnerable position as we do not have the choice, in many cases, of deciding whether or not we feel safe to disclose our status to them.”
>
> CONSULTATION PARTICIPANT FROM THE UNITED STATES

> “We need workplace policies and national laws to address discrimination but the solution to addressing stigma is education. Better visibility of people living with HIV in communities also helps to address the myth and fear surrounding HIV infection.”
>
> CONSULTATION PARTICIPANT FROM NIGERIA

These issues are closely related to each other and connect with multiple other issues: criminalisation, travel restrictions, access to treatment, and the ability of people with HIV to mobilise as a community to advocate on their own behalf. Stigma and discrimination against people living with HIV create barriers to prevention, treatment, care, and support.

People living with HIV who are part of key populations face multiple overlapping forms of stigma and discrimination. This includes women and girls, transgender people, young people, gay men and other men who have sex with men, sex workers, persons who use drugs, migrants, internally displaced people and prisoners.

Stigma and discrimination in workplaces, schools and universities limits opportunities to earn an income and provide for families, infringes on the right to work, and impedes social protection. There is a need for supportive, non-judgmental workplaces and policies. When stigma and discrimination occur in the community and family, people lose their main sources of physical, mental, and emotional support. In faith settings, a lack of knowledge about HIV, barriers to talking about HIV and sexuality due to moralising, the invisibility of people living with HIV within congregations, the linking of culture with religion, and the hierarchical structure of some religious communities can lead to, and pose barriers to addressing, stigma and discrimination.

Health care settings are a key location for stigma and discrimination, and privacy violations. When these occur, they may cause people living with HIV to avoid medical care, increase fear and internal stigma, and create emotional distress. Stigma and discrimination can lead to:

- Reduced standard of care and denial of services to people living with HIV and key populations.
- HIV-negative people being prioritised over people living with HIV in access to general health care in some resource limited settings.
- Violations of confidentiality of patient information.
- Inadequately trained health care workers in terms of HIV or key population-related technical knowledge and attitudes, including maintaining confidentiality.

Incidents of discrimination should be documented. While anti-discrimination and confidentiality laws and policies sometimes exist, in many countries there is a gap between these protections and the experience of people living with HIV. Stigma and discrimination acts as a barrier to people living with HIV being able to enforce their rights and seek redress for cases where violations of their rights have occurred. Current legal environments are inadequate for protecting people living with HIV.

Stigma, discrimination, and violations of confidentiality harm the health and well-being of people living with HIV and those who may be at risk of infection, including key populations. Maintaining the right to privacy in the face of initiatives to force people to disclose their HIV status in the name of HIV prevention is an on-going struggle in many places. Visibility may help reduce stigma but can make individuals living with HIV vulnerable to rights violations. Anti-stigma education at the local community level is crucial.

Sexual and reproductive health and rights

People living with HIV advocate for...

- Comprehensive access to appropriate sexual and reproductive health and rights (SRHR) services for all people living with HIV and key populations.
- Laws and policies that protect and promote the SRHR of people living with HIV as well as key populations.
- An immediate end to forced or coerced abortion and sterilisation of women living with HIV.
- The right of women to control their own bodies, including the power to negotiate safer sex.
- The rights of HIV-positive women to decide whether or not to become pregnant and universal access to contraception and pregnancy support services.
- SRH-related rights literacy training and counselling on SRH-related rights for people living with HIV, networks and communities, focusing on the rights of women and girls, men, transgender people, young people, sex workers, gay men and other men who have sex with men, prisoners, migrants, internally displaced people and people who use drugs.
- Increased training for healthcare providers to ensure the delivery of accurate, non-judgmental and supportive SRH services to people of all ages and key populations.
- Comprehensive education for young people about sexuality and SRHR, as well as training for their parents, guardians and healthcare providers.
- Integrated SRH and maternal-child health services.
- Women-led projects and supportive spaces,which empower women and strengthen their capacity to challenge practices that violate SRHR.
- Communities to support each other's rights, e.g. men advocating for women's SRH rights, heterosexuals advocating for lesbian, gay, bisexual and transgender SRH rights, older people living with HIV advocating for SRH rights for younger people living with HIV.

What are the main issues?

Sexual and reproductive health and rights include the rights of people to have fulfilling sexual lives and to choose whether or not to marry and have children, free from violence and coercion, with full information about their bodies, sexuality, reproduction, and with protection from sexually transmitted infections. People living with HIV share these rights equally with people who are HIV-negative or remain untested.

However, SRHR violations are reported, including: rape, sexual assault, and other forms of gender-based violence; forced or coerced abortion and sterilisation; forced early marriage for women; lack of access to information and ART to prevent vertical transmission; denial of education to young people about their rights; age of consent laws for SRH services; and, a failure to provide HIV and STI prevention and fertility services to women, men and transgender people living with HIV and key populations, including young people, gay men and other MSM, sex workers, persons who use drugs, prisoners, migrants and internally displaced people.

> “It is crucial to have women only spaces to address SRH and rights issues... We have been losing more and more funding for women's focused work... It is through the safety of women only spaces that many women can find the strength to challenge abuses.”
>
> CONSULTATION PARTICIPANT FROM THE UNITED KINGDOM

> “One of the major barriers to SRHR... is the attitude and knowledge of healthcare workers. We need to recognise that healthcare workers come from the community and often have the same prejudices and attitudes... so it is essential that they are supported with training [and] on being able to have some empathy towards key populations and being able to do their job without judgement.”
>
> CONSULTATION PARTICIPANT FROM SOUTH AFRICA

There are several challenges to ensuring respect for the SRHR of people living with HIV. Many people living with HIV are unaware of their rights. Rights literacy training and rights-related counselling could help in this regard. Gender-based and homophobic violence remain key barriers to ensuring the SRHR of people living with HIV, especially women, transgender people, and many key populations such as gay men and other men who have sex with men, and sex workers. People living with HIV across all genders report a lack of or denial of SRH services. HIV-related stigma is linked to challenges to ensuring SRHR. Healthcare workers may provide limited support for SRHR and are often reported to be violators of rights. Some faith communities present particular barriers for protecting SRHR.

Specific experiences and SRHR needs vary by population. Young people living with HIV need supportive, evidence-based SRH services as they transition through adolescence to adulthood. Women, men, transgender people, sex workers, gay men and other men who have sex with men, prisoners, and people who use drugs all have specific SRH needs.

Information about how previous fights for SRHR for people living with HIV have been won would be useful. This should include documenting efforts to combat gender-based and homophobic violence, forced or coerced abortion or sterilisation, or other forms of SRHR-related discrimination. Positive experiences of people living with HIV receiving the support and education they need to make their own SRH decisions should be documented as well.

In terms of health systems, there should be greater access to information and integration of services, including for key populations. Comprehensive, evidence-based sexuality education should be provided.

Ending criminalisation of HIV non-disclosure, potential or perceived exposure, or non-intentional transmission

People living with HIV advocate for...

- ➜ Comprehensive public health messaging, sexual health information, education, and support that emphasise shared responsibility for HIV prevention among HIV-positive, HIV-negative and untested individuals.
- ➜ The repeal or modernisation of laws that single out HIV or people with HIV, ensuring that similar risks and harms are treated alike.
- ➜ Alternatives to a punitive, regulatory approach that benefit public health and human rights. Such alternatives include a supportive legal and policy environment; restorative justice; and Positive Health, Dignity and Prevention.
- ➜ An automatic review for everyone prosecuted or convicted on a charge related to their HIV status if laws are changed.
- ➜ The limited use and fair application of existing laws through guidelines for:
    - > **police and prosecutors**: to support sensible investigations when a person living with HIV is accused of violating a law, and to protect the confidentiality of those with HIV who are accused of misconduct, and their sexual partners; and,
    - > **judges and juries**: to reduce bias and prejudice against people with HIV when deciding to convict or not.

> “There are no data indicating that the broad application of criminal law to HIV transmission will achieve either criminal justice or prevent HIV transmission... [Instead] governments should expand programmes which have been proven to reduce HIV transmission while protecting the human rights both of people living with HIV and those who are HIV negative”.
>
> SOURCE: UNAIDS AND UNDP (2008) CRIMINALIZATION OF HIV TRANSMISSION: POLICY BRIEF

- ➜ Education for health care workers, religious leaders, media, legislators, police, prosecutors, and judges about HIV stigma and its impact on HIV criminalisation.
- ➜ Community education, legal literacy, capacity-building and empowerment among people living with HIV and our networks:
  - > to increase understanding of the issues and implications of these laws, including why HIV criminalisation is a human rights issue
  - > to increase education about our legal vulnerabilities, rights, and responsibilities
  - > to improve access to justice for unjustly prosecuted individuals
  - > to assure our ability to protect ourselves and our partners
  - > to challenge unjust laws and prosecutions
  - > to ensure prevention programmes emphasise shared responsibility in prevention messages.

What are the main issues?

Many countries are using criminal laws to prosecute people living with HIV who are either accused of not disclosing their HIV status to their partners and/or who potentially expose them to HIV (with the minority of cases involving a complainant who alleges they acquired HIV from the accused). Although many laws and prosecutions are framed by politicians, prosecutors and media as being about ‘intentional’ or ‘wilful’ HIV transmission, this is almost never the case. Some 66 countries have HIV-specific criminal laws in at least one jurisdiction, and at least 47 countries have used either HIV-specific criminal laws or general criminal laws against individuals living with HIV.

Such laws and prosecutions do not recognise the role that stigma, discrimination, and gender-based and homophobic violence against people living with HIV play in decisions about disclosure. HIV criminalisation as well as laws that criminalise key populations – including sex workers, people who use drugs, and gay men and other men who have sex with men – have a direct, negative impact on the human, sexual and reproductive rights of people living with HIV and key populations, and doubly so for members of criminalised key populations who are also living with HIV.

In addition, such laws undermine public health messages of shared responsibility for HIV prevention among HIV-positive, HIV-negative and untested individuals, because relying on disclosure can foster a false sense that HIV prevention is someone else’s concern. Many people living with HIV are unable to tell a sexual partner because they are currently unaware they are living with HIV, and those who are aware may not feel safe to do so.

UNAIDS and international civil society advocates, including many people living with HIV, have publicly opposed the use of criminal laws, except in the exceedingly rare case where a person has malicious intent and does, in fact, transmit HIV.

Part of the collateral damage of HIV criminalisation is the fear, worry and uncertainty about how to avoid being arrested or prosecuted, often due to a lack of legal literacy among people living with HIV. It is important for people to understand the law, their rights and their responsibilities. Community dialogue and training on this issue are needed for empowerment, solidarity and advocacy.

> “These penalties are arbitrary and [tell] the population, people living with HIV/AIDS are dangerous to society. I think here we need a public policy directing more energy toward the seronegative population, the responsibility for remaining seronegative is unique and their responsibility.”
>
> E-CONSULTATION PARTICIPANT FROM PHILIPPINES

> “For every prosecution or person charged... I wonder about the damage caused by the investigations of allegations... the breaches of confidentiality, the public outing of people whether they are found guilty or not or whether charges are actually brought or not.”
>
> E-CONSULTATION PARTICIPANT FROM THE NETHERLANDS

Elimination of HIV-related restrictions on entry, stay and residence

> “I had some trouble studying in Russia because they make you take an HIV test to get a student visa. I remember feeling like a criminal for being there and I was very scared about what would happen if I got hurt or had to see a doctor.”
>
> CONSULTATION PARTICIPANT FROM THE UNITED STATES

People living with HIV advocate for...

- The repeal of any and all laws which apply HIV-related restrictions on entry, stay and residence.
- Strengthened partnerships with the International Labour Organization (ILO) and the private sector to address HIV-related restrictions on entry, stay and residence for migrant workers.
- Scale up of appropriate and accessible services and treatment for undocumented immigrants and migrant workers ensuring specific attention to key populations, and prioritising situations where lives are at stake, e.g. deportation to countries with limited or no HIV treatment access.

What are the main issues?

According to UNAIDS, approximately one in four countries has some restrictions on entry, stay or residence against people living with HIV. Advocacy to end such restrictions has had some high profile successes in recent years, including the United States and China in 2010, Fiji and Namibia in 2011 and the Republic of Moldova in 2012. However, many people living with HIV worldwide continue to find that they are unable to legally emigrate to be with family, for a job or education opportunity, or for medical care because of such restrictions. Others find themselves summarily deported if they test HIV-positive. These restrictions are rooted in stigma against people living with HIV.

> “Travel restrictions are a way of superficially addressing the country’s HIV/AIDS epidemic without committing the work and resources that are needed. It makes it seem like HIV is a problem only for people ‘outside’ the country.”
>
> CONSULTATION PARTICIPANT FROM THE UNITED STATES

These restrictions are matters of life and death: some people go without medication in order to travel or emigrate for employment; some people die in custody while awaiting deportation; others are denied access to medication; and, still others are deported without being informed of their HIV status.

HIV testing for the purpose of prohibiting people living with HIV entry, stay and/or residence has negative impacts, such as where mandatory or forced testing for visa requirements is undertaken (often without counselling), and where undocumented immigrants have no or limited access to HIV prevention, testing and counselling, treatment, care and support, and SRH services, and may face deportation. Further, even when a country rescinds such laws, countries often find other reasons to deport or prohibit entry for someone whose HIV status is known.

One of the advocacy challenges is that the human rights violations are perpetrated by one country against migrants or travellers from another country. In this situation, the country of origin may not be interested in intervening on the behalf of people living with HIV. In addition, people living with HIV who are nationals of countries with HIV-related travel restrictions may be discriminated against domestically, making it difficult for them to mobilise to end their country’s HIV-related travel restrictions.

Community mobilisation, strengthening and activism

Although these topics are presented separately, many are inter-related. For example, the greater and more meaningful involvement of people living with HIV and key populations requires well-funded capacity building for networks.

Community mobilisation, strengthening and activism are goals in themselves. It is also important to recognise that they are closely linked to human rights and prevention, treatment, care and support, which are discussed in other sections. Indeed, rights-based approaches to prevention, treatment, care and support will not be possible without effective community mobilisation, strengthening and activism. Nor will efforts to address the human rights contexts of HIV, especially for women and girls, young people, and key populations such as transgender people, gay men and other men who have sex with men, sex workers, persons who use drugs, prisoners, migrants and internally displaced people.

This section includes five topics:

- ➜ **Involvement of people living with HIV (in service delivery, policy and programming)**
- ➜ **Funding for the HIV response**
- ➜ **Engagement of key populations in networks of people living with HIV**
- ➜ **Networks capacity building**
- ➜ **People living with HIV and new science and research**

Involvement of people living with HIV (in service delivery, policy and programming)

People living with HIV advocate for…

- Strengthened understanding and application of the Greater Involvement of People Living with HIV (GIPA) principle amongst governments and people living with HIV.
- Opportunities and support for greater involvement and leadership from women living with HIV. Increased involvement and representation of key affected communities in the development and delivery of services and programmes, and in policy setting processes.
- Monitoring of GIPA and of levels of effective participation of people living with HIV.
- Increased visibility of people living with HIV in service delivery programming, including through the development of models of services the community would like to see from health care and other service providers.
- Capacity development for people living with HIV to strengthen effective participation at all levels of programme development, implementation, and M&E processes (for example, involvement in M&E frameworks and national level indicators for UNGASS). Recognition of people living with HIV as experts in these fields.
- Strengthened networks of people living with HIV that can exchange ideas and resources to more effectively achieve GIPA.
- Investment in further capacity building opportunities, mentorship programmes for people living with HIV, and programmes that facilitate the involvement of people living with HIV in the face of environments that present challenges to ongoing engagement.
- Support for organisations that focus on diverse and specific areas (e.g. treatment as prevention, services for youth, services for mothers and children, research organisations, etc.).
- Accountability for individuals or organisations representing people living with HIV.
- Strengthened engagement with networks of key populations and the full diversity of the community of people living with HIV.
- Strengthened engagement between local, regional and international networks of people living with HIV.
- Increased representation of people living with HIV in national parliaments.
- Support for communities in rural areas to challenge corruption and poorly functioning systems.

What are the main issues?

People living with HIV have an inherent comparative advantage (lived experience) in HIV-related fields. The meaningful involvement of people living with HIV should be promoted as a priority in the HIV response.

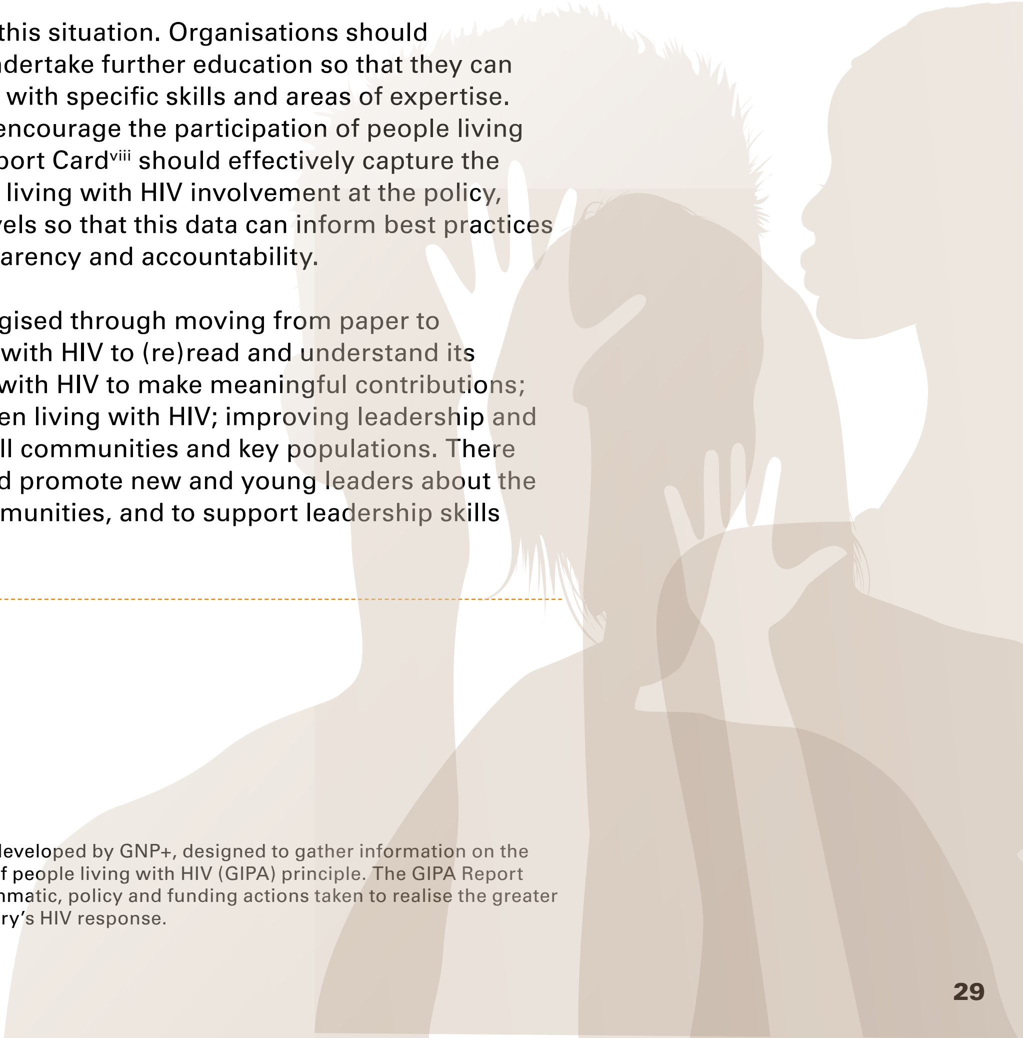
The involvement of people living with HIV builds dignity, self-esteem and helps to ensure that interventions are appropriate, effective and enhance the quality of life of the community of people living with HIV. The involvement of people living with HIV helps to develop skills beyond providing psychosocial support to participation in policy formulation, treatment access and research, which support people to be self-reliant.

However, the promise of the GIPA principle – the Greater and More Meaningful Involvement of People Living with HIV – has yet to be achieved in most settings. Several challenges have been identified. Skills to advocate and lobby decision makers remain limited, and networks of people living with HIV do not have sufficient resources to empower themselves or to mobilise their communities. HIV-positive individuals often face challenges around ongoing engagement, especially when they may be dealing with pressing problems, such as ensuring appropriate housing and income for themselves and their families, dealing with other health issues, or with stigma and discrimination based on their gender, age, sexuality, drug use or work. There is low investment and lack of platforms for skills transfer for people living with HIV leadership, organisational managers and programme developers. There are also limited resources to support capacity building and empowerment within the community of people living with HIV. Much remains to be done to ensure the leadership of women living with HIV achieves appropriate levels, and to nurture new leadership among young people. Engaging the full diversity of the community of people living with HIV also remains a challenge – from transgender people and gay men who have sex with men to persons who use drugs, prisoners, migrants and internally displaced people.

Community voices still remain tokenistic at the policy and decision-making levels in many cases, and people living with HIV often remain passive recipients of services with little ability to address discrimination. The risk of stigma and the discrimination from the community presents a challenge of disclosure. This situation leads to questions such as: How much influence do people living with HIV have? How can we have a meaningful impact? Political leaders often do not want to listen to people living with HIV, and people living with HIV often need to be cautious with what and how they are involved.

There are opportunities to improve this situation. Organisations should support people living with HIV to undertake further education so that they can complement their lived experiences with specific skills and areas of expertise. Likewise, health authorities should encourage the participation of people living with HIV. Tools such as the GIPA Report Card[viii] should effectively capture the successes and challenges of people living with HIV involvement at the policy, programme and service delivery levels so that this data can inform best practices and be replicated to increase transparency and accountability.

The GIPA principle could be re-energised through moving from paper to practice: encouraging people living with HIV to (re)read and understand its content; empowering people living with HIV to make meaningful contributions; promoting the engagement of women living with HIV; improving leadership and responsibility; and, engaging with all communities and key populations. There is a need for funding to sensitise and promote new and young leaders about the GIPA principle in countries and communities, and to support leadership skills transfer through mentorship.



[viii] The GIPA Report Card is an advocacy tool, developed by GNP+, designed to gather information on the level of application of the greater involvement of people living with HIV (GIPA) principle. The GIPA Report Card seeks to increase and improve the programmatic, policy and funding actions taken to realise the greater involvement of people living with HIV in a country's HIV response.

Funding for the HIV response

> “Civil society organisations need support and funds to fully understand the Investment Framework and be able to apply it to their own country contexts. The role of people living with HIV and key populations as [promoters of] critical enablers must be understood and accepted by governments. The UN agencies need to stand firmly behind civil society in ensuring this.”
>
> CONSULTATION PARTICIPANT

People living with HIV advocate for...

- ➜ Increased funding adequate to reach the 2015 Millennium Development Goals and targets for treatment, care and support, including for key populations.
- ➜ Increased national HIV funding from all countries, including in low- and middle-income countries.
- ➜ Diversified funding from governments, donors and the private sector.
- ➜ Increased funding for capacity building of people living with HIV to ensure strengthened positive community leadership, visibility and engagement.
- ➜ Funding for people living with HIV networks’ core operational and advocacy costs from sources other than government and donors.
- ➜ Resourcing for people living with HIV networks so that people living with HIV fully understand, and are able to take a leading role in the application of, strategic investment approaches at country level.
- ➜ Accountability of agencies and organisations that fail to deliver on their commitment to strengthen and support responses to HIV.
- ➜ Development and renewal of leadership, governance and accountability amongst organisations and networks of people living with HIV, including effective evaluation of what people living with HIV do well and what they can do differently and/or better as communities.
- ➜ Increased and strengthened collaboration between people living with HIV networks to share strategies, expertise and knowledge, and look for opportunities, synergies, and alignments.

What are the main issues?

In recent years, funding for the HIV response has declined, drastically affecting programmes and service delivery and contributing to the closure of some organisations and putting many others under severe financial constraints. HIV is no longer a priority in many countries or for the G8 and G20; we now have to compete with other development issues.

Decreased funding has also affected funding mechanisms such as the Global Fund Round 11 as well as networks of people living with HIV, which are finding it difficult to access core funds, resulting in reduced services and inability to pay staff. However, advocacy by people living with HIV and other stakeholders has resulted in some governments increasing domestic funding, with some governments considering tax-based initiatives to increase funding.

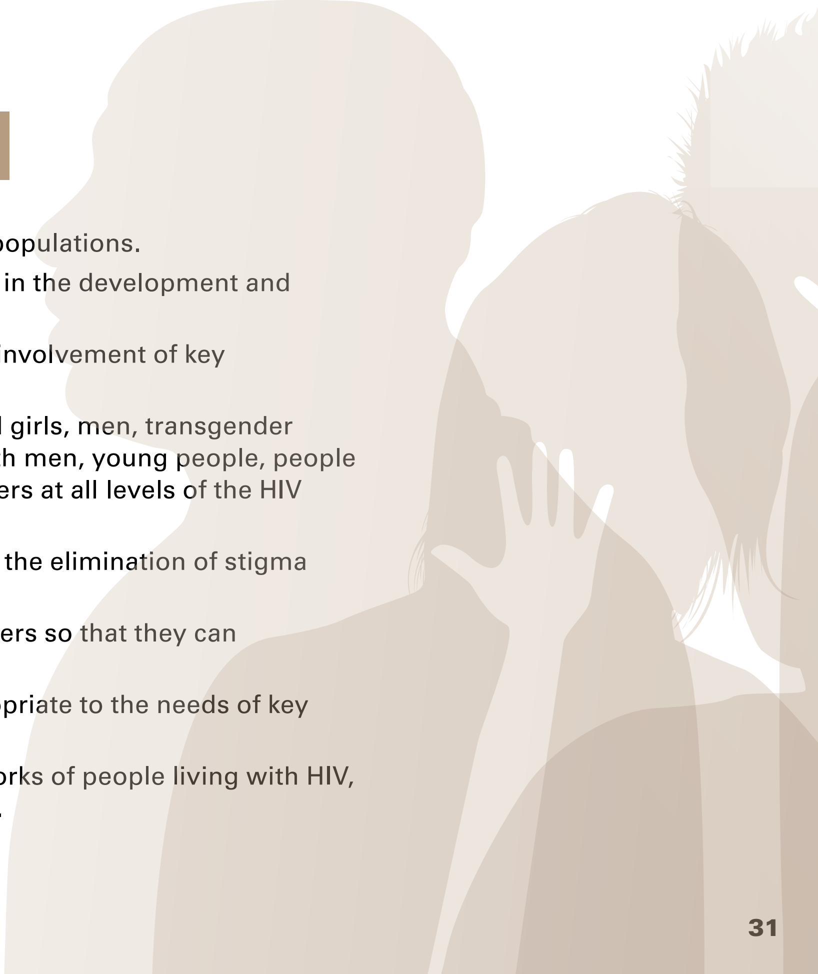
Many people living with HIV are unaware of dialogues related to the strategic investment approaches. There is need for transparent processes on how they are being conceptualised in terms of costing community service delivery and advocacy, and clarifying the role of CSOs, especially people living with HIV and key populations, in promoting and delivering critical enablers and basic programme activities. Funding and UN support needs to be provided to networks of people living with HIV in order for networks to fully understand the approaches and how they can be applied to countries. Communities should be sensitised about the approaches being discussed at global and country level to enable them to hold their governments accountable to a strategic approach to investment in their programming.

Transparency and accountability should be key issues for all community groups and similarly for governments, donors, the Global Fund, and UN agencies. It is time for the community of people living with HIV to have an increased say in assessing their own effectiveness and how well they are delivering. The community of people living with HIV needs to be more critical and vocal with agencies which were established to improve the HIV response when they do not use their resources effectively and do not deliver. Funding must be prioritised for organisations that are effectively addressing the HIV epidemic.

There is a need for increased financing for projects delivering health promotion at community level. People living with HIV should demand that resources be allocated to high impact areas, with networks collaborating more closely and sharing resources, and developing better methodologies and programmes to improve efficiency, effectiveness, equity and value for money. The sustainability and predictability of funding is vital, as is the need to maintain HIV as a critical development issue. There is a need to advocate for all countries to increase domestic HIV funding, including low- and middle-income countries. The private sector must contribute as well. Funding must be available to support food security and nutrition programmes.

Capacity building in resource mobilisation for networks of people living with HIV networks is a priority. This would address the lack of strategy for short and long term funding, the domination by large AIDS organisations leaving little or no room for smaller organisations, and inadequate monitoring of funds.

Engagement of key populations in networks of people living with HIV



People living with HIV advocate for…

- An end to stigma and discrimination against key populations.
- Rights-based, accountable, policies and practices in the development and delivery of health services for key populations.
- The removal of policies and laws that restrict the involvement of key populations.
- Increased meaningful participation of women and girls, men, transgender people, gay men and other men who have sex with men, young people, people who use drugs, sex workers, migrants and prisoners at all levels of the HIV response.
- Stronger community leadership and advocacy on the elimination of stigma and discrimination towards key populations.
- Strengthened capacity amongst HIV-positive leaders so that they can effectively address the health of key populations.
- Scale up of HIV programming sensitive and appropriate to the needs of key populations.
- The rightful place of key populations within networks of people living with HIV, in order to advocate together and act in solidarity.

> “I know that our network needs to be more inclusive when it comes to sex workers and men who have sex with men, but in my country these people are hidden because the laws target them as criminals. Unless we are able to change the laws and policies, we can never really be an inclusive network and advocate for all of the different needs of people living with HIV.”
>
> CONSULTATION PARTICIPANT

What are the main issues?

The community of people living with HIV is diverse. Some people living with HIV are more connected with key population networks and organisations than with networks of people living with HIV. The community of people living with HIV needs to recognise and accept the diversity of people living with HIV, be more open towards key populations, and promote the universality of human rights.

Key populations experience stigma and discrimination due to sexual orientation, occupation (e.g. sex work), gender, age, drug use, migration status, being in prison, and on the basis of other characteristics. This is exacerbated by legal barriers, including residency requirements and criminalisation of populations or behaviours.

These negative experiences drive people away from HIV testing and prevention, treatment, care and support services. There is also a lack of fundamental supports to meet the needs of key populations, including: lack of data on many populations; lack of interest, commitment and funding for programmes; lack of involvement of professionals; and, poor access to specific services.

Addressing the barriers to accessing prevention, treatment, care and support faced by key populations is essential in both concentrated and generalised epidemic contexts. For example, there is an emerging recognition of the epidemic among gay men and other men who have sex with men in low- and middle-income countries, but the need to develop programmes is often confronted with a strong level of homophobia among people living with HIV, among other stakeholders. The lack of non-opiate drug information and harm reduction strategies for people who use drugs in many parts of the world is another example. Likewise, there is a need for efforts to reject compulsory HIV and STI testing for sex workers, and HIV among transgender people has often received inadequate attention. Other barriers exist for a number of key populations.

Networks of people living with HIV must reflect the real diversity of the community at the local, national, regional and global levels. Only through inclusive networks will they be in a position to advocate effectively around the issues that affect the entire community. Networks of people living with HIV need to work alongside key population networks to remove the legal and policy barriers, which restrict people living with HIV from participating actively within the broader movement.

Networks capacity building

People living with HIV advocate for...

- ➜ Strengthened capacity of people living with HIV and key populations in key areas such as policy analysis and advocacy to enable effective leadership in policies and programme setting processes.
- ➜ Long term sustainable funding for capacity building of local, regional and international networks of people living with HIV.

- Mentoring and collaboration between organisations of people living with HIV from the Global North and Global South.
- Strengthened networks through partnerships with other organisations, networks, social justice movements and activists to share ideas, skills and resources to build greater capacity.
- Support for the development of networks of people living with HIV in settings where they do not exist.
- Equal employment opportunities for people living with HIV, including in government positions.
- Accountability mechanisms and improved governance for networks of people living with HIV to ensure organisations work in the interests of community with effectiveness and responsibility, and are able to show value-added.

What are the main issues?

For networks of people living with HIV to function effectively, capacity building is needed in a number of areas, both for individuals, networks and organisations – at the policy, programme and service delivery levels.

This includes general capacity building in key areas such as advocacy and lobbying skills, policy analysis, report writing and general writing skills, peer education, research literacy, treatment literacy, resource mobilisation, communications, governance, organisational and programme management, evidence-gathering, monitoring and evaluation, and fighting corruption. There is a need to create and share models of what works, particularly for grassroots community groups.

Mentoring programmes that link activists globally on issues such as free trade agreements, patents, cure research, etc. (without creating a dichotomy between low/middle-income and high-income countries) would help to close the knowledge gap between activists.

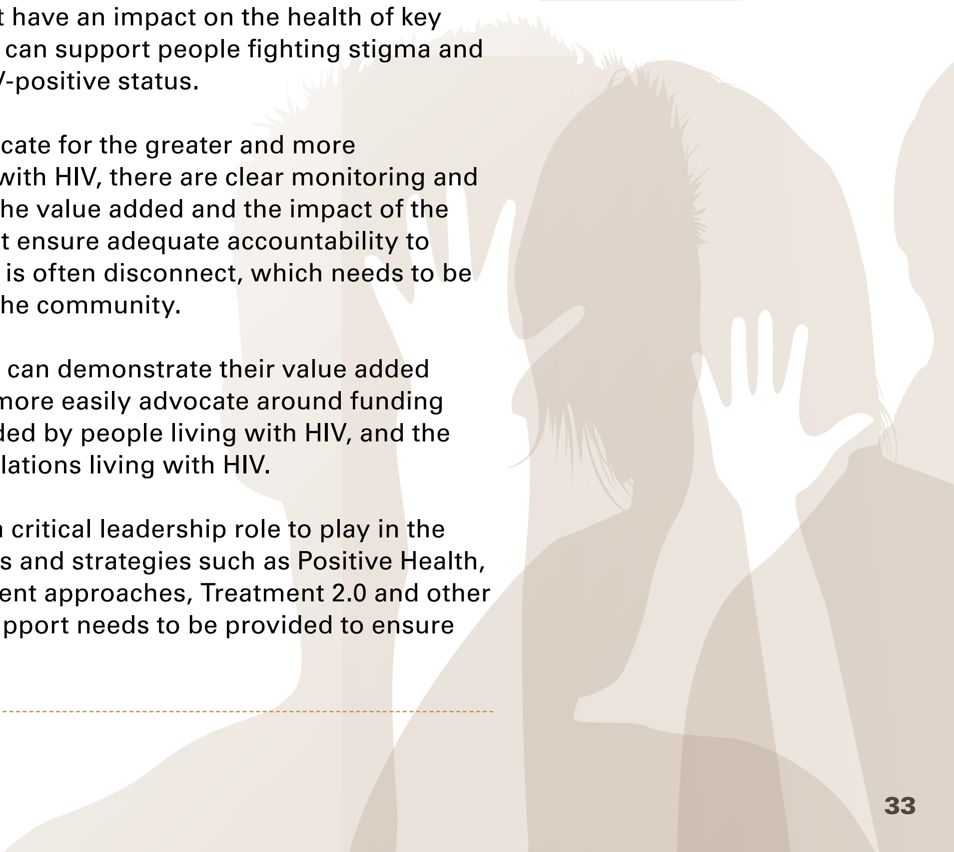
Building interpersonal and negotiation skills would help empower people living with HIV to demand improved service delivery in healthcare, and improve their ability to engage with government and non-governmental agencies. Likewise, building the capacity of the HIV-positive leadership would help them address issues affecting key populations by advocating for the design and implementation of rights-based policies and practices that have an impact on the health of key populations. Empowerment programmes can support people fighting stigma and discrimination related to disclosure of HIV-positive status.

It is essential that as the community advocate for the greater and more meaningful involvement of people living with HIV, there are clear monitoring and evaluation mechanisms, which measure the value added and the impact of the involvement. The same mechanisms must ensure adequate accountability to the constituents being represented, there is often disconnect, which needs to be addressed between representatives and the community.

Through more accountable networks that can demonstrate their value added to the HIV response, the community can more easily advocate around funding issues, including the unpaid labour provided by people living with HIV, and the need for funding specifically for key populations living with HIV.

Networks of people living with HIV have a critical leadership role to play in the implementation and adoption of initiatives and strategies such as Positive Health, Dignity and Prevention, strategic investment approaches, Treatment 2.0 and other approaches in national HIV responses. Support needs to be provided to ensure that such leadership can be realised.

> “It is becoming harder and harder to get core funding to do our fundamental work. We can only get programme funding, but no support for our organisation and its capacity. How do donors think we can survive? We are struggling to always justify the need for our network, why do we need to still justify GIPA?”
>
> CONSULTATION PARTICIPANT



People living with HIV and new science and research

People living with HIV advocate for…

- Increased research in key areas including cures, therapeutic vaccines, optimal therapeutic use of ARVs, use of ARVs for prevention, and other prevention options such as preventive vaccines and microbicides.
- Increased priority and funding from government and donors on new science and research.
- Meaningful participation of people living with HIV and key populations in all HIV research, including ethical review and community advisory boards, and at all stages of design, implementation, monitoring, evaluation, and communication.
- Universal application and monitoring of clear ethical guidelines that protect the human rights of research participants, and action when any research is assessed as violating those rights.
- Communication and availability of research findings and/or products to communities of people living with HIV and key populations in accessible and relevant ways.

> “People living with HIV should participate in designing appropriate referral and follow-up approaches that link HIV-positive people involved in HIV prevention trials to care, treatment and support services. People living with HIV should also be involved in designing the risk reduction counselling, recruitment, informed consent and retention strategies in trials.”
>
> CONSULTATION PARTICIPANT

What are the main issues?

Networks of people living with HIV have a crucial role to play in ensuring that biomedical and socio-behavioural research is being carried out for the benefit of individuals, as well as for broader public benefit. People living with HIV should be involved at all stages, including the design, implementation, ongoing monitoring and evaluation of research. Participating communities and countries should benefit from the research.

Networks of people living with HIV must be guardians of the rights of HIV-positive people who are participating in clinical trials, for example, by representing their interests on community advisory boards and by taking on roles as community outreach workers. Community advisory boards play an ombudsperson-type role ensuring that no research or trial is implemented until protocols are vetted and approved. People living with HIV, members of key populations and other researchers must serve as ‘ombudsman’ and be responsible for the implementation of safety guidelines, protection of human rights, ensure peer review mechanisms are in place, formulate ethical guidelines, conduct full risk assessments, ensure that standards of opt in/out are being adhered to, etc.

Different communities must have the necessary support and resources to be involved in research and trials, and know how research and trials could benefit them. This includes special considerations for key populations that may be particularly vulnerable, including women and girls, young people, sex workers, people who use drugs, transgender people, and gay men and other men who have sex with men. Some region-specific issues require attention: for example, how to handle the question of traditional practitioners (i.e. traditional medicine) in Africa in the context of research?

There is need to address scientific gaps including research into: sterilising and functional cures; optimal therapeutic use of ARVs; therapeutic and preventive vaccines; ARV- and non-ARV-based vaginal and rectal microbicides; how many people are on first- and second-line therapies, and why people are switched; and, the use of ARVs as prevention, e.g. PrEP, post-exposure prophylaxis (PEP) and TasP.

Suggested reading

Prevention, treatment, care and support

Increasing access to antiretroviral drugs for all those who need them

- ➜ WHO (2011). A new health sector agenda for HIV/AIDS: Advocacy brochure on the global health sector strategy on HIV/AIDS, 2011–2015.
  http://www.who.int/hiv/pub/advocacy_brochure/en/index.html
- ➜ Case Study: Treatment 2.0 Pilot in Vietnam – Early Progress and Challenges.
  http://xa.yimg.com/kq/groups/9727221/2107281222/name/VTN%20paperTreatment20%2Epdf
- ➜ WHO, UNAIDS (2011). The Treatment 2.0 Framework for Action: Catalysing the Next Phase of Treatment, Care and Support.
  http://www.who.int/hiv/pub/arv/treatment/en/index.html
- ➜ Third World Resurgence (2011). The Bangkok Declaration on Free Trade Agreements and access to medicines.
  http://www.twnside.org.sg/title2/resurgence/2012/twr259.htm
- ➜ ITPC (2011). Fact Sheet #4 Trade: Patents, Generic Drugs and Free Trade Agreements.
  http://www.itpcglobal.org/atomic-documents/11057/20005/4-Trade%20Fact%20Sheet.pdf

Prevention of vertical transmission

- ➜ Inter-Agency Task Team (IATT) for Prevention and Treatment of HIV Infection in Pregnant Women, Mothers and Their Children (2011). Preventing HIV and Unintended Pregnancies: Strategic Framework 2010–2015.
  http://www.unfpa.org/public/home/publications/pid/10575
- ➜ GNP+, ICW, ITPC (2012). Moving Beyond Lip Service: Meaningful Engagement of Women Living with HIV and Civil Society in Efforts to Prevent Vertical Transmission of HIV.
  http://www.four4women.org/sites/default/files/resources/file/global%20plan%20consultation%20report.pdf
- ➜ UNAIDS (2012). Promising practices in community engagement for the elimination of new infections in children by 2015 and keeping mothers alive.
  http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2012/20120628_JC2281_PromisingPracticesCommunityEngagements_en.pdf
- ➜ UNAIDS (2011). Global Plan Towards the Elimination of New HIV Infections among Children by 2015 and Keeping their Mothers Alive.
  http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/20110609_JC2137_Global-Plan-elimination-HIv-Children_en.pdf

Treatment as prevention

- ➜ GNP+ (2012). ART for Prevention. Position Paper.
  http://www.gnpplus.net/en/resources/positive-health-digity-and-prevention/item/130-gnp%20-position-on-treatment-as-prevention
- ➜ WHO (2012). Antiretroviral therapy for prevention.
  http://www.who.int/hiv/topics/artforprevention/en/index.html

HIV testing and counselling

- ➜ GNP+ (2011). HIV-related Stigma: Late Testing, Late Treatment.
  http://www.gnpplus.net/en/resources/human-rights-and-stigma/item/101-hiv-related-stigma-latetesting-late-treatment

- WHO (2012). Guidance on couples HIV testing and counselling – including antiretroviral therapy for treatment and prevention in serodiscordant couples. http://www.who.int/hiv/pub/guidelines/9789241501972/en/index.html
- WHO (2012). Service delivery approaches to HIV testing and counselling (HTC): A strategic policy framework. http://www.who.int/hiv/pub/vct/htc_framework/en/index.html

Treatment literacy

- International Treatment Preparedness Coalition (ITPC). http://www.itpcglobal.org/treatment_literacy

Diagnostics and monitoring (viral load, CD4 count and drug resistance)

- WHO (2012). WHO global strategy for the surveillance and monitoring of HIV drug resistance. http://www.who.int/hiv/pub/drugresistance/drug_resistance_strategy/en/index.html

Psychosocial support (and care and support more broadly)

- WHO (2008). Essential Prevention and Care Interventions for Adults and Adolescents Living with HIV in Resource-Limited Settings. http://www.who.int/hiv/pub/plhiv/interventions/en/index.html
- WHO (2012). WHO policy on collaborative TB/HIV activities: guidelines for national programmes and other stakeholders. http://www.who.int/tb/publications/2012/tb_hiv_policy_9789241503006/en/index.html
- Guidance on prevention of viral hepatitis B and C among people who inject drugs. http://www.who.int/hiv/pub/guidelines/hepatitis/en/index.html

Human rights

Eradicating stigma and discrimination (and protecting the right to confidentiality and privacy)

- The People Living with HIV Stigma Index. www.stigmaindex.org
- Stigma and Discrimination: Hindering Effective Responses. NGO Delegation to the UNAIDS PCB. http://unaidspcbngo.org/?p=10832
- Sprague L, Simon S and Sprague C, (2011). Employment discrimination and HIV stigma: survey results from civil society organisations and people living with HIV in Africa. *African Journal of AIDS Research.* http://unaidspcbngo.org/wp-content/uploads/2012/08/Sprague-Simon-Sprague-AJAR-article.pdf

Sexual and reproductive health and rights

- GNP+, ICW, Young Positives, EngenderHealth, IPFF, UNAIDS (2009). Advancing the Sexual and Reproductive Health and Human Rights of People Living with HIV: A Guidance Package. http://www.gnpplus.net/en/programmes/sexual-and-reproductive-health-and-human-rights/policyguidance/1511-advancing-the-sexual-and-reproductive-health-and-human-rights-of-people-living-with-hiv
- IPPF, UNFPA, WHO, UNAIDS, GNP+, ICW, Young Positives (2009). Rapid assessment tool for sexual and reproductive health and HIV linkages: Generic guide. http://www.unfpa.org/public/publications/pid/1350

Ending criminalisation of HIV non-disclosure, potential or perceived exposure, or non-intentional transmission

- The Oslo Declaration on HIV Criminalization (2012). www.hivjustice.net/oslo
- Report of the Global Commission and the Law (2012). www.hivlawcommission.org
- HIV Justice Network. www.hivjustice.net

- Bernard EJ and Bennett-Carlson R, UNAIDS (2012). Criminalisation of HIV Non-disclosure, Exposure and Transmission: Background and Current Landscape. http://www.unaids.org/en/media/unaids/contentassets/documents/document/2012/BackgroundCurrentLandscapeCriminalisationHIV_Final.pdf

Elimination of HIV-related restrictions on entry, stay and residence

- UNAIDS. Eliminating travel restrictions. http://www.unaids.org/en/targetsandcommitments/eliminatingtravelrestrictions/

Community mobilisation, strengthening and activism

Involvement of people living with HIV (in service delivery, policy and programming)

- GNP+, UNAIDS (2011). Positive Health, Dignity and Prevention: Policy Framework. http://www.gnpplus.net/images/stories/PHDP/GNP_PHDP_ENG_V4ia_2.pdf
- GIPA Good Practice Guide. http://www.gnpplus.net/images/stories/Empowerment/GRC/GIPA_Good_Practice_Guide.pdf
- Denver Principles. http://www.actupny.org/documents/Denver.html

Funding for the HIV response

- Aidspan. www.aidspan.org
- The Investment Framework. http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(11)60702-2/fulltext
- UNAIDS (2011). A new investment framework for the global HIV response. Issues Brief. http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/JC2244_InvestmentFramework_en.pdf
- Community Mobilisation on the Investment Framework. http://icssupport.org/investment-framework-community-mobilization-2012

Engagement of key populations in networks of people living with HIV

- Global Forum on MSM and HIV (MSMGF). www.msmgf.org
- Global Network of Sex Work Projects (NSWP). www.nswp.org
- International Network of People who use Drugs (INPUD). www.inpud.net
- African Black Diaspora Global Network (ABDGN). www.abdgn.org
- Global Advocates for Trans Equality. www.transactivists.org
- Centre of Excellence for Transgender Health. www.transhealth.ucsf.edu
- NSWP+ and ANSWP+ (2012). NSWP+ and ANSWP+ launch statement. http://www.nswp.org/news-story/apnsw-and-nswp-launched-swff#.ULsaR_o8coQ.facebook

Networks capacity building

- Network Capacity Analysis Toolkit. http://www.aidsalliance.org/Publicationsdetails.aspx?Id=278

People living with HIV and new science and research

- Good Participatory Guidelines. http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/JC1853_GPP_Guidelines_2011_en.pdf
- GNP+ (2010). New Prevention Technologies Advocacy Agenda. http://www.gnpplus.net/images/stories/PHDP/NPT_Advocacy_Agenda_English_v4.pdf
- GNP+ (2010). New Prevention Technologies Toolkit. http://www.gnpplus.net/images/stories/PHDP/NPT_Toolkit_ENG_web.pdf

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