POSITIVE HEALTH, DIGNITY AND PREVENTION IN ETHIOPIA:

FINDINGS AND RECOMMENDATIONS FROM STUDIES LED BY PEOPLE LIVING WITH HIV

Acronyms

ARV	Antiretroviral
CCM	Country Coordinating Mechanism (for delivery of Global Fund interventions)
CSO	Civil Society Organisation
DfID	UK Department for International Development
GIPA	Greater Involvement of People Living with HIV and AIDS
GNP+	Global Network of People Living with HIV
GTF	Governance and Transparency Fund
IEC	Information, education and communication
ICW	International Community of Women Living with HIV/AIDS
LACA	Local Action Committee on AIDS
LGBT	Lesbian, gay, bisexual and transgender
LTA	Leadership Through Accountability
MSM	Men who have sex with men
NACA	National Agency for the Control of AIDS
NEP+	Network of Networks of HIV Positives in Ethiopia
SRHR	Sexual Reproductive Health Rights
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNGASS	United Nations General Assembly Special Session on HIV/AIDS

Contents

Acronyms 02
Overview 04
The epidemic 04
National Laws and Policies 05
Human rights 06
Health and other economic and social rights 07
Women and other key populations 08
Health and Wellbeing 09
Prevention, Treatment and Care 09
IN FOCUS: Sexual and reproductive rights in the context of programmes to prevent vertical transmission of HIV 11
Economic and Social Rights 14
Affected by poverty but left out of mitigation strategies 14
Women fall behind on education, jobs and food security 15
Human rights 16
Violations and discrimination 16
Stigma and exclusion 17
Key populations 18
Empowerment of people living with HIV – the GIPA Report Card 18
Recommendations 20
Notes 21

Overview

Ethiopia is the second most populous country in Africa. The country has nine Regional States and two City Administrations. These are subdivided into over 800 administrative woredas (districts), which are further divided into kebeles, the smallest administrative unit. Ethiopia is one of the countries with the lowest per capita income, estimated at 390 USD per annum and over a third of the population live below the absolute poverty line. Nevertheless, it has one of fastest growing economies among non-oil producing countries in sub-Saharan Africa. In recent years, the country has seen rapid progress in economic growth, expansion of social infrastructure, and in improving healthcare.

People of Ethiopia:

- The majority (83.9%) reside in rural areas
- The average household size is 4.7
- The average life expectancy is 51 years for males and 53 years for females
- Women in the reproductive age group constitute 24% of the population

The epidemic

With an estimated adult prevalence of 1.5%, Ethiopia[1] has a large number of people living with HIV (approximately 800,000) and about 1 million children orphaned by AIDS There is wide variation in HIV prevalence among administrative regions, and between urban and rural settings as confirmed by Demographic Health Survey (DHS) 2011: urban adult HIV prevalence was 4.2% (women 5.2%, men 2.9%) while rural adult HIV prevalence was 0.6% (women 0.8%, men 0.5%).

The 2012 *Country Progress Report* published by the Government of Ethiopia summarises the progress made and challenges remaining in its current response:

> **Progress:** Recent reports show that Ethiopia is one of the sub-Saharan countries demonstrating more than a 25% decline in new HIV infections. Antenatal care (ANC) sentinel surveillance data show that prevalence of new infections among pregnant women 15-24 years of age has declined from 5.6% in 2005, to 3.5% in 2007, and 2.6% in 2011. Likewise, DHS data show that use of preventive methods and the number of people who were tested for HIV and utilising treatment and care services has increased. For example, the number of people tested for HIV annually has increased from forty thousand in 2005 to nearly ten million by 2011. Similarly, the proportion of women aged 15–49 who received an HIV test in the last 12 months and who know the results has increased from just 1.9% in 2005 to 20.0% in 2011.
>
> **Challenges:** The epidemic is still huge as nearly 800,000 are living with HIV, more are orphaned, and the rate of new infections is declining but still high, and possibly expanding to newer population groups and geographic areas. This calls for a more robust and targeted response while at the same time scaling-up existing interventions among high-risk population groups. Key challenges include low utilisation of some of the existing services (especially PMTCT), emergence of new at-risk population groups (young girls engaged in transactional sex), low coverage of interventions for most at risk populations, and ensuring quality of available services.

[1] All data in the Overview section from Country Progress Report on HIV/AIDS Response, 2012, Federal Democratic Republic of Ethiopia, April 2012

National Laws and Policies

Ethiopia's national response to the HIV epidemic is guided by the national policy on HIV/AIDS issued in August 1998. This policy was elaborated initially through a five-year (2000-2004) national strategic framework and then replaced by a strategic plan for the succeeding four years (2005-2008), also supplemented by the Multi-sectoral Plan of Action for Universal Access to HIV Prevention, Treatment, Care and Support in Ethiopia 2007–2010. In addition, a number of other HIV specific policies (see list below)[2] as well as policies in other sectors such as education and health guide the national response.

In 2011, the second five year strategic plan (SPM II 2010/11-2014/15) was developed based on lessons and experiences from the previous strategic plan and reflecting the current state of the epidemic. The SPM II has five thematic areas: creating an enabling environment; intensifying HIV prevention; increasing access to and improving quality of chronic care and treatment; intensifying mitigation efforts against the epidemic; and strengthening the generation and utilisation of strategic information. Moreover, in 2011, a road map for implementation of SPM II was finalised, as well as manuals on a minimum service package for orphans and vulnerable children and for most at risk populations.

The 2011 *Criminalisation Scan*[3] study found that Ethiopia has many laws and policies enacted to protect people living with HIV and also promote an enabling environment for achieving universal access to HIV prevention, treatment care and support:

- The National HIV/AIDS Policy (1998) recognises that HIV is not only a health problem but also a development problem in Ethiopia. The overall goal of the policy is to provide an enabling environment for the prevention and control of HIV in the country;
- The Constitution prohibits any discrimination based on race, nationality, colour, gender, language, religion, politics, social background, wealth, birth, or any other status. The phrase "other status" has been interpreted to prohibit discrimination on the basis of HIV status;
- The Federal Civil Servants Proclamation and Labour Proclamation prohibit compulsory HIV testing for the purpose of employment. The first clause states "there shall be no discrimination among job seekers or civil servants in filling up vacancies because of their ethnic origin, sex, religion, political outlook, disability, HIV/AIDS or any other ground".

In response to the historic UN Political Declaration on HIV/AIDS (UNGASS 2001), governments around the world including Ethiopia undertook to scale up their response and report on their progress regularly. The 2012 *Country Progress Report* published by the Government of Ethiopia states that *"the national HIV/AIDS programme environment can be characterised as conducive, with high political commitment, strong coordination and monitoring mechanisms, and with an increasing trend to accommodate and engage stakeholders including civil society, PLHIV, bilateral and multilateral partners. The national programme has mechanisms to periodically review its performance and identify emerging needs and gaps."*

[2] The National Monitoring and Evaluation Framework for the Multi-Sectoral Response to HIV/AIDS in Ethiopia (HAPCO, December 2003); the National Guidelines for HIV Counselling in Ethiopia (2007); the National Health Communication Strategy for 2005-2014 (October 2004); the Guideline for an effective Community Mobilization Strategy (HAPCO, May 2005); the Guidelines for Implementation of Antiretroviral Therapy (2005); the Guidelines for Prevention of Mother-to-Child Transmission of HIV (2007); the National Anti-Retroviral Therapy (ART) Strategic Communication Framework (March 2005); and, the Guidelines for Use of Antiretroviral Drugs (2005)

[3] Global Criminalisation Scan, Ethiopia: Country Assessment, GNP+, NEP+, December 2011

However, most of the respondents participating in the 2010 *PLHIV Stigma Index*[4] research had limited awareness both about the UN Declaration of Commitment on HIV and AIDS, and the National HIV/AIDS Policy. **And, surprisingly, more respondents were aware of the UN Declaration than the National Policy.**

The money

The National Health Accounts Survey[5] indicated that national HIV/AIDS expenditure amounted to USD$248,000,114 in 2007/08. This was the largest spending on a specific disease in the country accounting for more than 20% of total spending in the health sector. The bulk of this, i.e. 84%, was from external sources, while government spending constituted 11% of the total expenditures. Out of pocket expenditures for HIV diagnosis, treatment and care accounted for 3.5% of the total expenditures. In fact, **PLHIV shoulder the brunt of expenditures, spending more than five-folds of the amount the general population spent on healthcare.** Other sources, including private sector and local NGOs accounted for 1% of the expenditures. Health in general and the response to the HIV epidemic is a national priority as evidenced by steadily increasing health expenditure: some regions have allocated 15% of public expenditure; public and some private sector organisations have earmarked 2% of their annual budget for the HIV response.

Human rights

The Constitution of Ethiopia forms the trunk of the national legal framework from which the other laws stem. It provides a range of rights to all men, women, boys and girls and most of these rights have relevance in the context of HIV. The rights, especially, to non-discrimination and equality before the law, access to social services including health and education, participation, employment, to marry and start a family, the right to privacy, dignity and reputation, are particularly significant in terms of promoting and protecting the rights of people living with HIV (Fikremarkos, 2007).

Although Ethiopia does not have a special law prohibiting discrimination on the grounds of HIV status, Article 25 of the Constitution can be read to provide this protection: *All persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall guarantee to all persons equal and effective protection without discrimination on grounds of race, nation, nationality, or other social origin, colour, sex, language, religion, political or other opinion, property, birth or other status.*[6]

In addition, whilst Ethiopia has the National HIV/AIDS Policy, labour laws and other laws and policies to protect people living with HIV and also promote an enabling environment for achieving universal access to HIV prevention, treatment care and support, the *Criminalisation Scan* study found no reported cases where these protections had been invoked by people living with HIV. This is at odds with the recorded cases of discrimination and mistreatment based on HIV status that have been reported by NEP+. Therefore, the protective laws and policies are either not known to people living with HIV, who do not invoke their protection, or enforcing authorities have a poor record of enforcing them.

The study listed few examples of punitive laws that could have a negative impact on responses to HIV:

- Intentional and negligent transmission of HIV is criminalised;
- Same sex, sexual relations are prohibited;
- Use of narcotics substances is illegal.
- Gaining from the proceeds of prostitution or maintaining brothels is prohibited.

[4] The PLHIV Stigma Index, Ethiopia, NEP+, July 2011
[5] As quoted in Country Progress Report on HIV/AIDS Response, 2012, Federal Democratic Republic of Ethiopia, April 2012
[6] Constitution of the Federal Democratic Republic of Ethiopia: Article 25

Criminalisation of HIV transmission: The study also found that Ethiopia has one legal instrument that has direct application in governing criminalisation for HIV non-disclosure, exposure and transmission. This law is the 2004 revision of the Criminal Code of Ethiopia.[7] The relevant clause in the legislation does not refer to HIV specifically. The law treats the act of transmitting HIV in the same way as transmitting other 'communicable human diseases.[8] The law criminalises the intentional or negligent transmission or spreading of communicable human disease. Actual transmission, rather than exposure is a crime. Whilst data on these prosecutions was hard to come by, the study found four cases that had been successfully prosecuted; three in Addis Ababa (the capital city) and one in Bahirdar (Amhara regional city). This, however, does not mean that there are no other cases or prosecutions in other parts of the country. Three of the defendants were initially charged with other sexual offences (same sex sexual acts and rape), however in the course of investigations the HIV status of the defendants were revealed and thus they faced additional charges for attempting to transmit HIV. In one case, the charge appears to have been based entirely on an offence of transmitting HIV. The prosecuting officials can request that a defendant in a sexual crime be tested for HIV, however, in all the above cases there was no proof that the victims were actually infected with HIV as a result of the acts of the accused, and there was no evidence of additional investigations undertaken to ascertain this fact. This raises the question whether HIV was an aggravating factor in relation to the other offences or whether the HIV transmission was the second and separate offence that the defendants were accused of.

Sexual acts of a homosexual nature (between people of the same sex) are crimes under the Ethiopian criminal law.[9] Therefore men who have sex with men (MSM) are liable for a penalty up to three years of imprisonment. As well as the state laws, tribal laws and religious edicts strongly condemn homosexuality. As a result, MSM and other same sex couples do not identify in public are highly stigmatised and live in fear of persecution from the state authorities as well as society. **The study did not find any HIV services targeted at men who have sex with men, despite this population being a population at high risk of HIV infection.**

The law prohibits producing, making, trafficking or using poisonous or narcotic and psychotropic substances without special authorisation.[10] Needles and syringes are not mentioned in any of the legislation relating to illegal drug use. This is probably because this paraphernalia is not associated with illegal drugs traditionally used in Ethiopia. **The study did not find any HIV prevention services for people who inject drugs.**

The mere fact of selling sex is not a criminal act under the Ethiopian law. However, the law prohibits individuals from gaining from the proceeds of prostitution and also prohibits individuals from maintaining or keeping brothels.[11]

Health and other economic and social rights

Ethiopia has ratified the Millennium Development Goals (MDGs) and is committed to the attainment of these goals by 2015. Health is at the centre of the national Programme for Accelerated and Sustained Development and Ending Poverty (PASDEP). The country has endorsed a Health Sector Development Plan (HSDP), which focuses on prevention and mitigation of priority health problems such as HIV, tuberculosis, malaria, diarrheal diseases and common childhood and maternal illnesses. The country is currently implementing the fourth plan. In 2003, the government launched the Health Extension Programme to deliver a package of basic and essential healthcare, including HIV preventive services. To date, more than 30,000 health extension workers have been deployed.

[7] Criminal Code of Ethiopia, Proclamation No. 414/2004
[8] Article 514 of the Criminal Code
[9] Criminal Code of Ethiopia 2004: Section II - SEXUAL DEVIATIONS. Article 629 - Homosexual and other Indecent Acts
[10] Criminal Code of Ethiopia 2004: Article 525 - Producing, Making, Trafficking in or Using Poisonous or Narcotic and Psychotropic Substances.
[11] Criminal Code of Ethiopia 2004: Article 634 - Habitual Exploitation for Pecuniary Gain

According to 2012 *Country Progress Report*, Ethiopia has made significant strides in healthcare delivery. The number of health facilities and the health work force has steadily grown in the last two decades, increasing coverage and use of healthcare. This has contributed to improved health status of the population, notably maternal and child health. However, wide regional and urban/rural variations remain, for example, while 76 percent of urban women accessed ANC only 26 percent of rural women did so, underscoring the challenge for overcoming barriers for access and use of services in rural areas.

Women and other key populations

Ethiopia's Constitution states *"Women shall have equal rights with men in the enjoyment of the rights and protections guaranteed by this Constitution to all Ethiopians... The State has the duty to guarantee the right of women to be free from the influence of harmful customary practices. All laws, stereotyped ideas and customs which oppress women or otherwise adversely affect their physical and mental well-being are prohibited... Women shall have the right to demand that their opinions be heard on matters of national development policies, on plan and project implementation, and in particular, on projects affecting their interests. Women shall have the right of access to education and information on family planning and the capability to benefit thereby so as to protect their good health and prevent health hazards resulting from child birth."*[12] The national health policy also identifies that due consideration is needed for mother and child health, emphasising inter-sector collaboration for family health and population planning.

HIV-discordant couples are one of the highest at-risk population groups in Ethiopia. However, the magnitude of the problem is not well documented. The fear of stigma and discrimination against the HIV-positive partner hinders discussion and decision on use of preventive methods. The situation is worse for women as they are less likely either to share their positive status or to freely ask for the HIV status of their partner due to gender, economic, and cultural barriers

According to the 2012 *Country Progress Report*, the Government of Ethiopia has identified HIV-discordant couples, sex workers, men in uniformed services, long-distance truckers, mobile workers and cross border populations as populations who are most-at-risk and/or highly vulnerable populations (MARPs) to HIV infection based on available data. Emerging at-risk groups include young women who are often engaged in trans-generational sexual networks with older men in return for money and gifts. **Young girls engaged in transactional sex have low risk perception; and thus inconsistently use condoms.**

The other emerging key population groups engaged in transactional sex include domestic workers, daily labourers, and waitresses. A recent study in selected towns that identified these groups, indicated that, despite an increased risk of HIV infection observed among the groups, targeted HIV prevention is either often lacking or when available, inadequate.

Contrary to the early days of the epidemic, HIV prevalence studies about sex workers in the last decade are scanty, limiting our understanding of the situation in this population group. Data on at-risk population groups indicate higher prevalence of HIV compared to the general population. However, the size and distribution of these emerging at-risk groups, their sexual networks and bridging populations remains largely unknown, making determinations of the scope of the epidemic in these groups largely speculative.

[12] Translation of the Ethiopian Constitution http://www.africa.upenn.edu/Hornet/Ethiopian_Constitution.html

Health and Wellbeing

Prevention, Treatment and Care

Key issues emerging from the PLHIV Stigma Index research include:

Deciding to take an HIV Test: Overall the majority of respondents (more than 80 percent) said that it was their own decision to undergo a test. The most common reason for HIV testing cited by the majority of people living with HIV, both from urban and rural areas, was referral by health professionals following symptoms observed during medical check-ups. Personal initiation of testing accounts for about a third of the total cases, but it varies by gender. Male respondents were more likely to have been tested of their own accord than female (37.5 percent versus 28 percent, respectively). Female respondents were more likely to have been tested for HIV as a result of death, illness or when aware of the HIV status of their husband or partner.

Access to medicines: In Ethiopia, the free antiretroviral therapy (ART) programme was launched in 2005 and decentralisation of ART services to health centres was initiated in 2006. While there have been impressive gains in number of people starting treatment, there are many who discontinue and are lost to follow-up.

In line with national statistics, 89 percent of the respondents reported taking ART at the time of the survey. Nearly 64 percent of the respondents reported taking medication to prevent or treat opportunistic infections (OIs). The use of ART and OI medication was higher among male and urban respondents in comparison to their female and rural counterparts.

People living with HIV who reported that they were not taking ART and OI medication were further asked about their perceived access should the need for such treatment arise. Relatively a larger proportion of HIV-positive people residing in rural areas reported that they either did not have access to ART or did not know about where to access ART (34 percent) and OI medication (70 percent). The corresponding figures for urban respondents were 18 percent and 46 percent, respectively.

Support from healthcare professionals: About 68 percent of the respondents noted that they had constructive discussions with health professionals on their HIV-related treatment options in the year prior to the survey. The proportion of people living with HIV that had constructive discussion on sexual and reproductive health (SRH), sexual relationship(s), emotional well-being, drug use, etc in the same period was 54 percent. Urban residents and male respondents were more likely to conduct constructive discussions with health professionals on these subjects compared to rural and female respondents, respectively.

Coercion by healthcare professionals: Only three out of five of the respondents reported to have received counselling about reproductive options after being diagnosed as HIV-positive. **Two in five of people living with HIV reported that they have been advised by health professionals not to have children after being diagnosed as HIV-positive.** Nearly four percent of the respondents claimed to have

been forced by health care workers to undergo permanent sterilisation because of their HIV status. Some 14 percent of the respondents also revealed that their ARV treatment was provided conditional to the use of certain forms of contraception.

Sexual and reproductive health and rights: The research found the gender variation in the experience of reproductive health / rights related issues to be statistically significant – see below.

PLHIV experience of reproductive health and rights	Men	Women
Ever received counselling about reproductive options after being diagnosed as HIV-positive	57.4	61.6
Ever advised by health professional not to have children after being diagnosed as HIV-positive	36.5	43.9
Ever coerced by health care professional into being sterilised since being diagnosed HIV-positive	2.9	4.3

IN FOCUS: Sexual and reproductive rights in the context of programmes to prevent vertical transmission of HIV

> **"Mother-to-child HIV prevention work is very poor; the focus is mainly on pills and condom distribution. I guess there are more things to consider for a comprehensive reproductive health service focusing on PLHIV needs and circumstances".**
> **GIPA Report Card[13]**

Ethiopia has adopted the UN four-pronged strategy to prevent vertical transmission of HIV as a key entry point to HIV care for women, men and families. Technical interventions, including antiretroviral medications, satisfactory obstetric care, effective health system management and resource allocation, as well as addressing gender bias, are all part of the comprehensive national PMTCT programme. Addressing all four prongs has the potential to impede systemic failures in efforts to prevent vertical transmission.

According to the annual HIV and AIDS multi-sector response, 2009-2010, the Federal HIV and AIDS prevention and Control office reports that the number of health facilities that provide vertical transmission services grew from 32 in 2003/4 to 1352 in 2009/10. However, greater efforts are needed to ensure and expand availability of such services because the number of health facilities that provide vertical transmission services is still under half of the total number of health centres that could provide these services. In cities like Addis Ababa, where many private health facilities provide maternal and child health services, it is recommended to integrate vertical transmission services in the private health sector as well.

The current national HIV, PMTCT and reproductive health policy is well designed and addresses the issues of sexual and reproductive health and rights of women living with HIV. The prevention of vertical transmission guidelines were developed based on WHO recommendations. However, the implementation of these guidelines at community level is poor due to a lack of resources, infrastructure and limited knowledge of current policy among implementers at community level.

There are a variety of interventions on the prevention of vertical transmission and SRHR being implemented by the government, NGOs, CBOs, 'anti-AIDS' clubs, mothers groups and associations and networks of people living with HIV. These interventions, whilst encouraging, still need better coordination, integration and need to ensure sustainability and quality.

[13] The GIPA Report Card, Ethiopian Country Assessment 2010. NEP+, GNP+, March 2011

In 2010-11, NEP+ and NNPWE conducted an assessment of the needs of women living with HIV in the Amhara and Somali regions of Ethiopia as part of the *Sexual and Reproductive Health and Rights study*.[14] Below are some key issues raised by the women interviewed.

The majority of HIV-positive women interviewed reported that they benefited considerably from the services given by mothers groups to help access health facilities for ANC and services to prevent vertical transmission.

> **"The mother support group provide information in the morning to the crowd of women who come there for treatment, whether positive or negative, about condom and family planning in general, using this opportunity, the women would get the information" (FGD, F,Gigiga)**

The quality of services to prevent vertical transmission, provide sexual and reproductive health advice and other HIV services vary from region to region and within also within the regions; the quality decreases in rural areas. The main factors for low quality of services are shortage of qualified doctors, laboratory equipment, medication and absence of some essential services.

> **"There are instances where the professionals are overcrowded and we are asked to wait [considerably] longer than expected. I had [that] experience when I delivered my baby. Because the doctor was very busy. I had to wait for him and I started bleeding which should not normally happen when you are about to deliver. It could be fatal and my baby had to be [undergo treatment] for days because of that" (FGD, F ,Desse)**

The majority of those interviewed are HIV-positive women who have accessed services to prevent vertical transmission and have children who are HIV-negative. Most women said that as a result of accessing these services their knowledge not only about vertical transmission, but also reproductive health, family planning, ANC, child feeding and HIV treatment has improved.

> **"When a woman decides to get pregnant, first she consults her doctor and if her CD4 count is low she would start ART and if she decides to use family planning she would be given choices about the methods she uses, there may be implants, pills, etc." (FGD, F, Gigiga)**

The key causes of the low uptake of services to prevent vertical transmission and treatment are a lack of awareness about SRHR, ANC, the prevention of vertical transmission and HIV treatment and their availability in health care facilities. Although the level of HIV-related stigma and discrimination varies over time and is experienced differently among people living with HIV, stigma remains a key barrier to accessing HIV treatment, care and support services. Misconceptions about HIV, based on religious beliefs, are a significant barrier for accessing HIV treatment especially amongst the Muslim community.

> **"The stigma is also there. A pregnant woman who is positive would not risk being isolated from her partner, neighbours, family and friends. So she prefers staying at home and avoids visits to the health facility." (Amhara, HAPCO, int)**

The significant distance between health facilities and the homes of people living with HIV is another barrier to accessing HIV services. As most health facilities are in urban areas, women living in rural areas cannot access professional health care because of lack of transportation and lack of money to afford these services.

[14] Advancing the Sexual and Reproductive Health and Human Rights of People Living with HIV. An Assessment of the needs of women living with HIV in the Amhara and Somali regions of Ethiopia. NEP+, GNP+, June 2011

Gender inequality is another factor preventing women from accessing health services. As women in the areas of study are often economically dependent on their husbands, they often lack the power to make decisions on family planning and their own sexual and reproductive health. The participation of men in services to prevent vertical transmission and ANC services is very low in both of the study sites.

> **"My husband refused to test and stopped me from accessing the service and that is why I had to raise HIV positive child" (FGD, F, Dessie)**

Some women still are not able to negotiate on their sexual and reproductive health and rights:

> **"I was this kind of man. I want everything my way. When I wanted a child, she says no. I deliberately stopped her from taking contraceptives and she was pregnant with my second child." (FGD, Men, Bah)**

Findings from NEP+'s study PLHIV Stigma Index confirmed many of the issues raised by women in the above study. In this study, 73 percent of men and 80 percent of women living with HIV reported to have a child/children; and 28 percent of these respondents reported having a child/children known to be HIV-positive, indicating the very low levels of vertical transmission service utilisation in the country. When asked if they have ever been given antiretroviral treatment to prevent vertical transmission of HIV during pregnancy, only 18 percent of those who were HIV-positive during pregnancy answered in the affirmative. Among those who reported that they have received comprehensive prevention of vertical transmission services, nearly 15 percent said that they were not given information or education about healthy pregnancy and motherhood as part of the programme.

Economic and Social Rights

Affected by poverty but left out of mitigation strategies

Using the World Bank's 1.25 USD per day per person as the cut-off point, **95 percent of female and 93 percent of male respondents in the *PLHIV Stigma Index* were reported to be living below extreme poverty line.** Although this is not a large enough sampling that can be compared to the national statistics which indicate that 39 percent live below 1.25 USD/ day, it demonstrates a very high level of extreme poverty among people living with HIV. This may be an indication of the fact that HIV is disproportionately affecting the poor and/or that HIV is causing people to be poor.

Despite the fact that nearly all of the respondents of the *GIPA Report Card* study strongly agreed that Ethiopia has a poverty reduction plan and/or strategy in place, less than 20% of respondents strongly agreed that the poverty reduction plan and/or strategy has been adequately reassessed with the input of people living with HIV to reflect the differing impact of HIV on women and men.

Graphic 1

Women fall behind on education, jobs and food security

The *PLHIV Stigma Index* revealed many instances of how women have less access to resources and opportunities to control their own lives.

Women living with HIV are overrepresented in the divorced/separated and widowed categories compared to men, while the latter were predominantly married or cohabiting. A higher proportion of men reported to be sexually active (61 percent) than women (39 percent).

More than three-quarters of men living with HIV had attained at least primary school education while only 56 percent of their female counterparts did the same.

The proportion of unemployed women was far higher than the male respondents (25 percent female respondents unemployed vs. 14 percent males). Female respondents were particularly noted to have lower monthly income (a median of 300 Birr and mean of 468 Birr) compared with the 400 Birr median and 574.4 Birr mean monthly income of male respondents.

In general, **three out of ten respondents live in households where there was no adequate food for at least 1-10 days in a month** and a fifth of the respondents have no access to adequate food for 11-20 days in a month.

Human rights

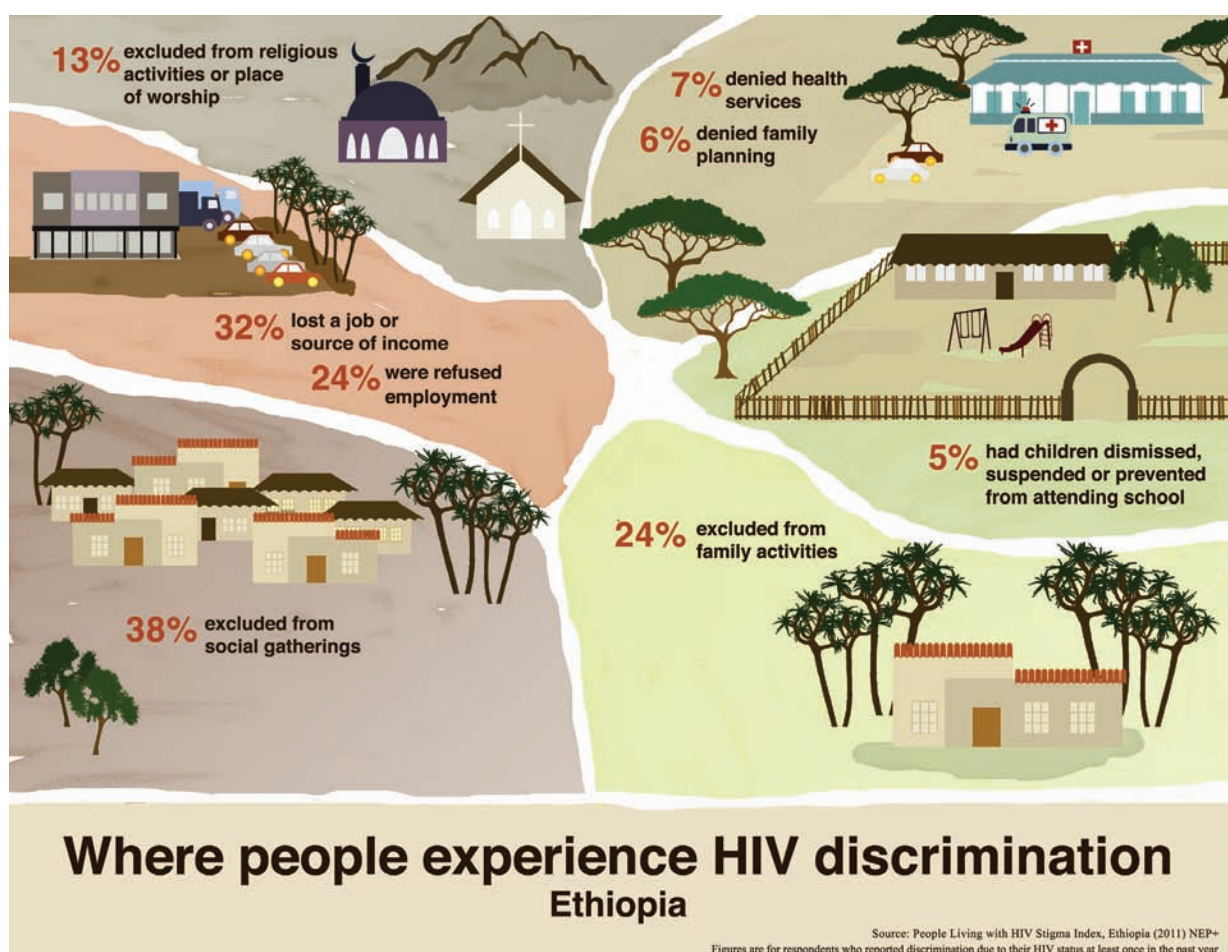
Violations and discrimination

Research for the *PLHIV Stigma Index* found that one in every six of people living with HIV reported experiencing some form of human rights violation. Somali, Gambella and Benishangul-Gumuz are the regions where violations are reportedly more widespread. The study showed that more than half of those who had experienced violations did not take any legal action. Many people living with HIV do not believe that taking legal measures would bring a satisfying outcome. Female respondents in particular feel intimidated and were afraid of undesirable consequences that may follow their action. Lack of adequate resources to follow up the case was the other reason that prohibited particularly those from rural areas from taking a legal action.

In the *Human Rights Count* study a human rights violation was said to have been committed when a person is discriminated against as a result of actual and presumed HIV-positive status. A total of 168 incidences of violations were reported by 106 respondents, as some respondents experienced multiple violations. **The majority of these human rights violations (62.5%) were inflicted on HIV-positive women.**

The study findings show that the **right to work, the right to adequate housing, the right to marry and found a family, the right to property and freedom from torture, degrading and inhuman treatment** are the five most commonly violated rights of people living with HIV in Ethiopia. Almost 70% of the violations took place from 2003 to 2011. This finding indicates that human rights violations based on HIV status are not relegated to history but are still taking place.

Graphic 2



The majority of respondents reported suffering psychologically and nearly half reported suffering economically and socially as a result of the violations.

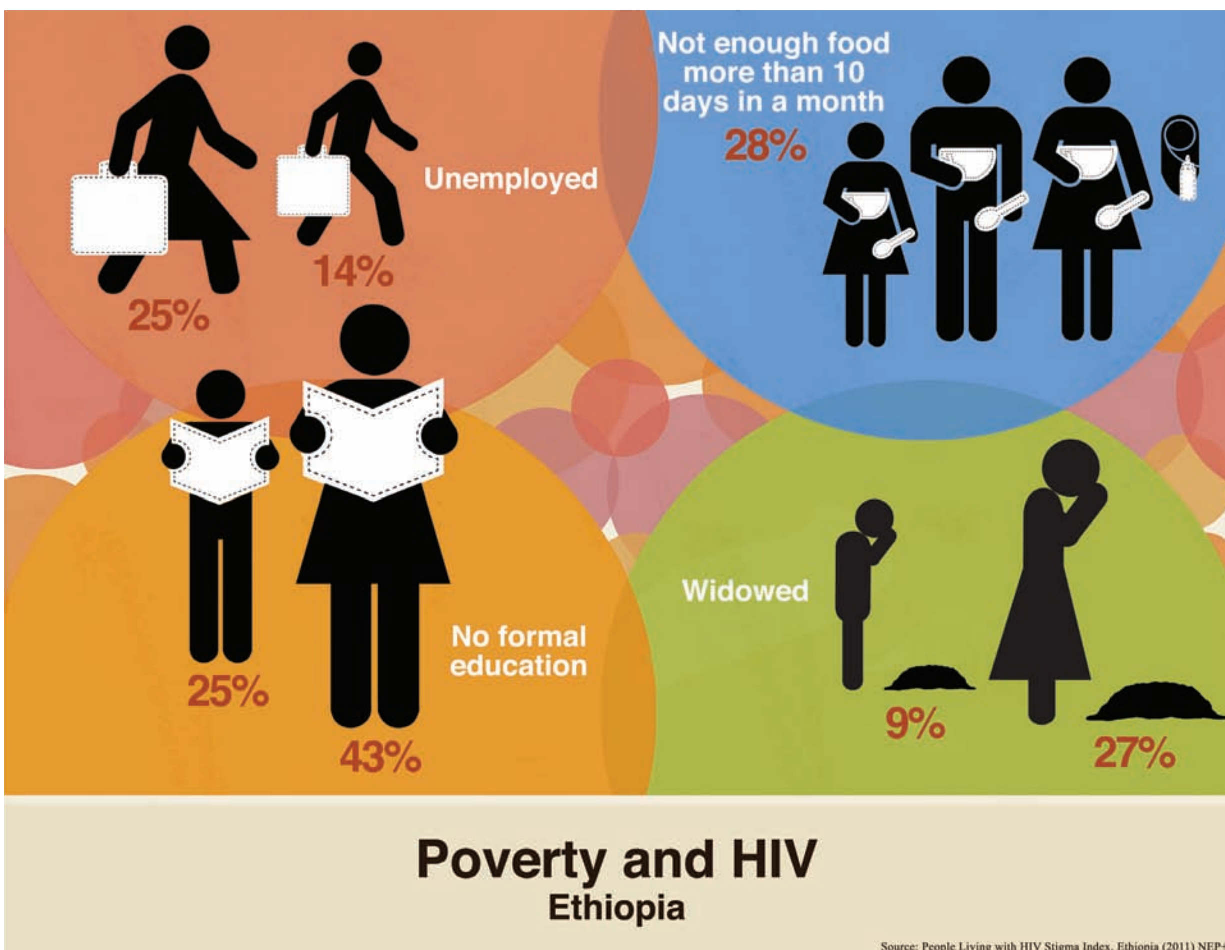
Human rights violations are often left unreported. Only one third of respondents said they had reported the violation to relevant authorities, and women were less likely to do so than men. One reason for this may be that less than half the respondents reporting knowing of the existence of protective laws that prohibit human rights violations against people living with HIV. Women and those with less education were less likely to be aware of such laws.

Men were three times more likely to be identified as the perpetrators of human rights violations than women. What is very worrying here is the fact that the largest numbers of these violations were committed by family members, followed by colleagues and neighbours.

Stigma and exclusion

Gossip was the most common way of stigmatising people living with HIV, as reported by 69 percent of the respondents of the *PLHIV Stigma Index*. Nearly 11 percent of people living with HIV reported that they were physically assaulted at least once in the year preceding the survey. When asked about their relationship with the perpetrator, more than half (54 percent) reported that they were from outside the household who was/were known to them. Nearly 20 percent of the assault cases were reported to have been inflicted by the spouse/partner or another member of the household. In short, almost three-fourth of the violent assaults on people living with HIV were perpetrated by either their family members (spouse/partner/other household member) or by people outside the family who were known to them. One-third of people living with HIV reported to have been verbally insulted, harassed and/or threatened at least once within the year before the survey. Some 76 percent attributed such an act exclusively to the HIV status of the respondents while additional 17 percent noted the cause to be both HIV status and other reasons.

Graphic 3



Key populations

Disclosing that one belongs to, or has association with, a social or behavioural group that the society at large is disdainful of, is very difficult. This is particularly true in traditional societies such as in Ethiopia where social norms are highly valued and where 'deviants' are disrespected and stigmatised. According to responses in the *PLHIV Stigma Index* study, about three-quarters of people living with HIV said that they did not belong to any of the population subgroups listed in the survey, nor were they in the high-risk behaviour categories. The pattern in this regard was the same for both men and women, except that three percent of female respondents mentioned that they have been engaged in sex work. The "migrant worker" category followed by "indigenous group" were the subgroups mentioned by a higher number of respondents. All other categories accounted for less than one percent of the responses. **However, it is worth mentioning that respondents who revealed that they were gay, lesbian or men having sex with men make up a total of 0.3 percent of the respondents. Given the fact that these are taboo topics in Ethiopia, it is likely that the actual proportion of interviewee in these categories may be higher than this.**

About 13 percent of respondents came from households that have one or two orphans living with them. Five percent of these households had three or more orphan members.

Empowerment of people living with HIV – the GIPA Report Card

What is Greater Involvement of People living with HIV (GIPA)?

The GIPA principle was endorsed by 192 United Nations member states in 2006. The origins of the GIPA principle started in 1983 in Denver (US), when people living with PLHIV first voiced and demanded that people living with HIV should be included at every level of decision-making. This became known as the Denver Principle, and it states that: *"PLHIV be involved at every level of decision–making; for example, serve on the boards of directors of provider organisations, and participate in all AIDS-related meetings with as much credibility as other participants, to share their own experiences and knowledge"* (UNAIDS 1999).

The results in the *GIPA Report Card* show that over time, substantial progress has been made in Ethiopia towards the meaningful involvement of people living with HIV, in decision-making processes on issues that influence their lives. This progress was well articulated and exhibited in the new strategic plan for intensifying the multi-sectoral HIV and AIDS response in Ethiopia (SPM II). **However, the new SPM II provides modest space for PLHIV involvement. It does not explicitly speak about the GIPA principle or ways to reinforce it.**

> **"For me meaningful implies that I am allowed to decide on matters that have an effect on my life, that I am actively leading or participating in a program or in planning a project, and involved in all aspects of an intervention, that my contribution is recognized, and that responsibility is assigned to me".** GIPA report

The National HIV and AIDS Plan

There were diverging opinions among respondents about whether the national HIV strategic plan includes the GIPA Principle as a sign of commitment by the government and as recognition for NEP+'s contribution in the response to HIV. However, GIPA is not explicitly articulated in most of the relevant documents. Implementation and reinforcement of the GIPA principle are still far from acceptable and adequate attention and resources do not exist to promote GIPA.

GIPA at State and Regional Levels

Most respondents acknowledged that the GIPA principle is exercised to a certain extent both at the state and regional levels but it is not always well recognised. Respondents felt that the principle is more recognised at the central level than in the regions.

Policy Development

The majority of respondents recognise that people living with HIV can officially participate at any stage of the national HIV policy development process. However, feelings were mixed about the meaningfulness of this involvement at the policy formulation level, as policy development usually takes place at a higher level, and participation is through NEP+. Some also believed that the capacity limitations of people living with HIV, hinder their active contribution, and that the involvement of people living with HIV is more common at the programme implementation stage than at the conception stage.

Universal Access

Over 68% of those interviewed were aware of universal access commitments and targets. Only about a quarter of the respondents strongly agree and about 46% somewhat agree that people living with HIV were meaningfully involved in the universal access target-setting process.

Representation and Networks of People Living with HIV

Nearly 80% of respondents somewhat or strongly agreed that people living with HIV are represented in one way or another on various decision-making bodies at national, regional and local levels. However, most felt that they were still not adequately and effectively represented. Participation through a limited number of network members is not considered to be very effective and communication is restricted or limited on issues of common concern.

Opportunities for Involvement

The Ethiopian government has demonstrated strong political will and commitment to address HIV. Programmes like the accelerated expansion of free ART have significantly improved the survival rate and quality of life for people living with HIV. In recent years, the role of associations of people living with HIV has significantly enhanced the national HIV response. NEP+ is a legitimate representative of people living with HIV in the country, and is a member of several decision-making bodies, including the National AIDS Council (NAC), the national management board, and the Country Coordinating Mechanism (CCM) for the Global Fund to fight AIDS, Tuberculosis and Malaria (GFATM). NEP+ is one of the principal recipients of GFATM Round 7 funding. HIV is now more than ever mainstreamed as a core activity of many public agencies, NGOs, and the private sector.

Barriers to Involvement

The most commonly cited barriers to involvement are the poor social and economic status of people living with HIV coupled with stigma and discrimination. Additional barriers that were mentioned included capacity limitations (as most staff members of organisations of people living with HIV have low levels of skills and there is inadequate staffing) and inadequate funding for the organisations and networks.

Recommendations

Reform of laws/policies

- Engage people living with HIV in developing laws, policies and guidelines relating to HIV, including those aiming to reduce stigma, discrimination and human rights violations.
- Include stigma-reduction initiatives in the national plan and budget.
- Put in place ways to measure progress on addressing stigma, discrimination and human rights violations.
- Raise awareness of negative impact of criminalising HIV transmission and other punitive laws amongst judges, prosecutors and police.
- Formally include the GIPA principle in the SPM II and its monitoring and evaluation framework and develop a National GIPA Plan.

Addressing human rights violations, discrimination and stigma

- Promote stigma-reduction programmes in workplaces, schools and healthcare facilities through developing policies, providing regular training and involving peer educators and counsellors.
- Promote positive living by people living with HIV and empower them to know and assert their rights.
- Mobilise communities and undertake social action to involve different stakeholders (from religious and traditional leaders to community workers and the police) in efforts to reducing stigma and discrimination.
- The Ethiopian Human Rights Commission (EHRC) should investigate human rights violations of people living with HIV routinely and free of cost.

Prioritising women and other key populations

- NEP+ should engage with networks of key affected populations to better understand the impact of punitive laws on their access to HIV services.
- Increase the involvement of women living with HIV in developing, implementing and monitoring policies and programmes.

Access to comprehensive healthcare

- Integrate sexual and reproductive health into all HIV treatment, care and support programmes.
- Scale up community based programmes, strengthen mentor mother groups and outreach workers to improve access and uptake of ANC and services to prevent vertical transmission of HIV, especially in rural areas.

Promoting economic and social rights

- Integrate input from people living with HIV into the national poverty reduction plan, and include a focus on the differing impact of HIV on women and men.
- Advocate for budget support to hire people living with HIV in organisations working on HIV.

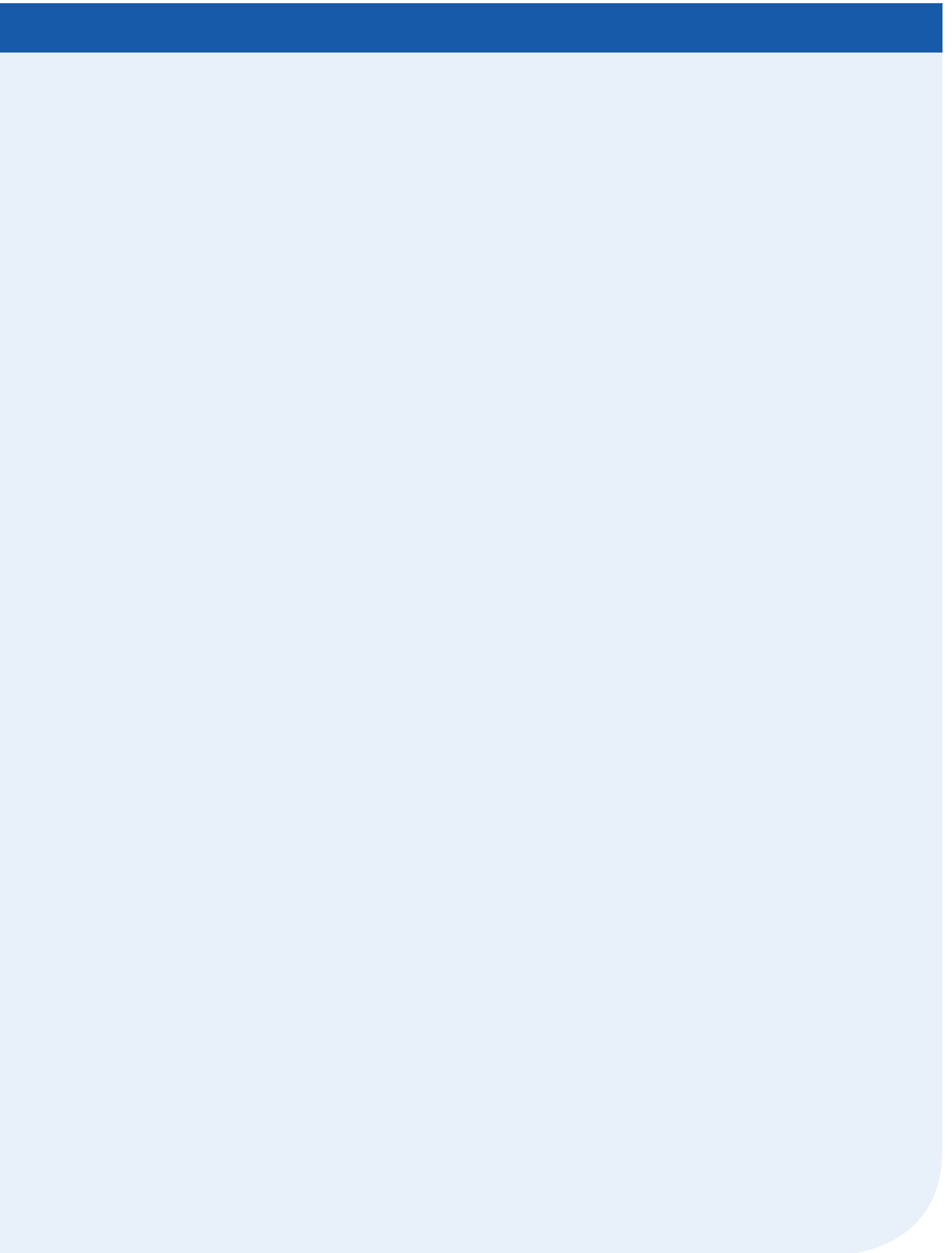
Published by:
Network of Networks of HIV Positives in Ethiopia (NEP+)
Arada Sub City, Kebele 13/14 H.No 551/2
Arat Kilo In front of Ginfile Bridge,
P.O.Box: 780 Code-1250

Website: www.nepplus.org
Email: aelwha@ethionet.et

Some rights reserved: This document may be freely shared, copied, translated, reviewed and distributed, in part or in whole, but not for sale or use in conjunction with commercial purposes. Only authorised translation, adaption and reprints may bear the emblems of GNP+ or NEP+.

© 2013 Network of Networks of HIV Positives in Ethiopia (NEP+)

NEP+, GNP+ (2013). Positive Health, Dignity and Prevention in Ethiopia. Findings and Recommendations from Studies led by People Living with HIV. NEP+, Addis Ababa, Ethiopia.



Published by:
Network of Networks of HIV Positives in Ethiopia (NEP+)
Arada Sub City, Kebele 13/14 H.No 551/2
Arat Kilo In Front of Ginfile Bridge,
P.O.Box: 780 Code-1250