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# **HUMAN RIGHTS COUNT!**

**Key findings of the pilot studies in  
Kenya, Nigeria and Zambia**



Network of Zambia People  
Living with HIV/AIDS (NZP+)



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The Human Rights Count! is one of five evidence-gathering tools being implemented through the HIV Leadership through Accountability programme. The programme combines specific HIV evidence-gathering tools, national AIDS campaigns and targeted advocacy to achieve Universal Access to prevention, treatment, care and support. For more information about the HIV Leadership through Accountability programme please visit [www.hivleadership.org](http://www.hivleadership.org).

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# Introduction

## Human Rights Count!

Despite various international declarations emphasising the importance of human rights in national responses to HIV, many countries are yet to develop effective strategies to address the human rights abuses suffered by people living with HIV (PLHIV) on account of their HIV positive status. Human rights violations, stigma and discrimination have a serious negative impact on prevention efforts and the accessibility and effectiveness of treatment, care and support. Left unchallenged, human rights violations against PLHIV will have a negative impact on achieving Millennium Development Goal 6, as well as many other national and international development goals.

The Human Rights Count! is a programme initiated and led by the Global Network of people living with HIV (GNP+) to document HIV-related human rights violations against people living with HIV as a result of their sero-positive status. The documentation is based on a PLHIV-driven methodology. The main aim of the programme is to decrease the number of human rights violations against people living with HIV by coordinating evidence informed advocacy against these violations.

This report summarises the key findings from the pilot implementation of the Human Rights Count! in Kenya, Nigeria and Zambia.

## HIV Leadership through Accountability programme

The HIV Leadership through Accountability programme is a collaboration between the Global Network of people living with HIV (GNP+), the World AIDS Campaign (WAC), national networks of PLHIV and national Civil Society campaign platforms. The programme is funded by UKaid from DfID and combines specific HIV evidence-gathering tools, national AIDS campaigns and targeted advocacy for Universal Access. The programme will run for five years and involve 15 countries in total.



# Human Rights Count!

National networks of PLHIV in Kenya, Nigeria and Zambia are leading the effort to document the experiences of people living with HIV and have employed a number of internationally tested, validated tools, aimed at strengthening the evidence on five key areas:

- Stigma and discrimination (The People Living with HIV Stigma Index)
- The level of involvement of people living with HIV (The GIPA Report Card)
- Documenting and analysing current experiences in criminalisation of HIV transmission (The Global Criminalisation Scan)
- Documenting and analysing human rights violations against PLHIV (Human Rights Count!)
- Sexual and Reproductive Health and Rights of PLHIV (Advancing the Sexual and Reproductive Health and Rights of PLHIV : A Guidance Package) supporting PLHIV networks to engage in national processes for the development and/or adaptation of sexual and reproductive health services for key populations

## Methodology

GNP+ developed a concept for networks of PLHIV to lead the process of systematically documenting HIV-related human rights violations. A questionnaire to guide data collection was subsequently developed after extensive consultations involving among others PLHIV and human rights organisations among others. In 2009, the project was piloted in Kenya, Nigeria and Zambia by networks of PLHIV working in partnership with human rights organisations.

Data were collected from 10 states in Nigeria, 4 cities in Kenya and 6 districts in Zambia. One of the factors considered in the choice of study sites in each country was the participation of both urban and rural based respondents. The questionnaires were administered by a data collection team comprising members of the PLHIV networks. Prior to the fieldwork, the teams underwent a standardised training developed and facilitated by the AIDS & Rights Alliance for Southern Africa (ARASA) aimed at improving their understanding of human rights and HIV and how to conduct the Human Rights Count! study.

Respondents were primarily recruited from the PLHIV support groups and in some cases, antiretroviral therapy (ART) sites. Participation was voluntary. Between October 2009 and March 2010, experiences of rights violations were recorded from 53 respondents in Kenya, 40 respondents in Nigeria and 28 respondents in Zambia. Except for Zambia, the majority of respondents were women.



## Limitations of the study

This multi-country study had a number of limitations. Firstly, the findings are based on relatively small non-random samples, which limits their generalisability. Secondly, participation was restricted to those who volunteered and were willing to have their experiences documented and there is a possibility that such respondents may have different characteristics from PLHIV who declined to participate. Finally, the questionnaire did not adequately address how the respondents could objectively identify an action that constitutes a human rights violation on the basis of HIV status. Nonetheless, the study presents useful findings to guide further research and inform the design of interventions to curb human rights violations in the context of HIV.

# Human Rights Count!

## Key findings

### 1. PLHIV experience violations of their rights on account of their HIV positive status

The results from all the three countries reveal that the human rights of PLHIV are being violated in various settings with complaints ranging from murder (in one case in Kenya) and torture to discrimination at work; in healthcare facilities and within the family. In most cases, respondents reported having suffered multiple human rights violations.

In Kenya, acts or omissions associated with the right to health were the most frequently cited. Results from the Zambian study show that violations of the right to work and non-discrimination were the most frequently reported. In Nigeria, the majority of the respondents reported having suffered violation of the right to non-discrimination. There were a number of rights abuses documented in only one or two of the countries in the study as illustrated in figure 1 below.

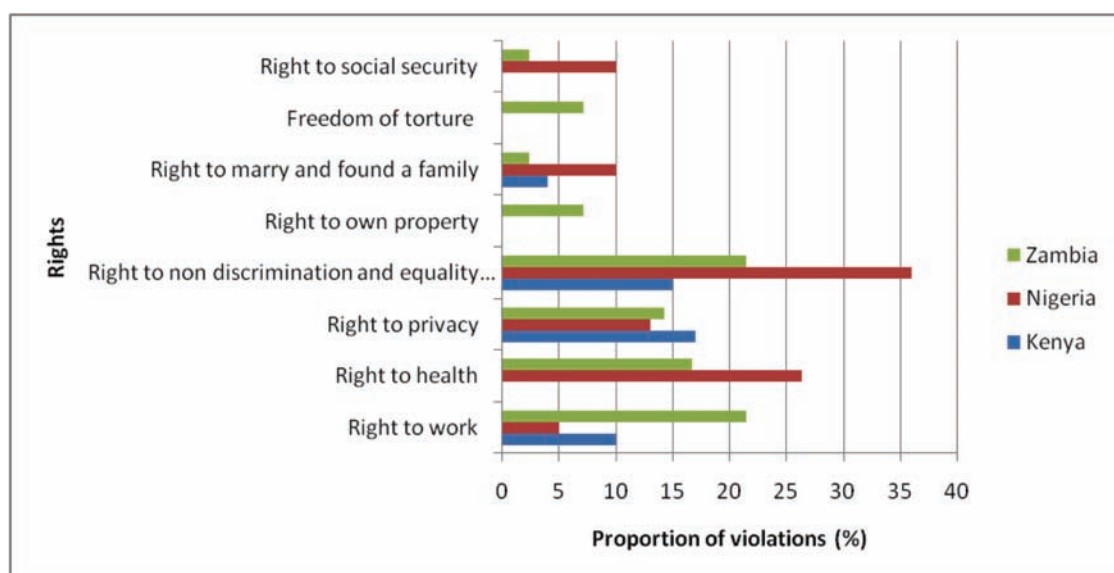


Figure 1: Human rights violations against PLHIV, selected results

Despite their low frequency, a number of documented cases bear particular significance as they underscore the range of rights abuses associated with being HIV positive. For instance, cases of respondents being denied to marry suggest the need for a greater focus on interventions that would safeguard the sexual and reproductive health rights of PLHIV.



## 2. PLHIV rarely report human rights violations to the appropriate authorities.

Analysis of the results from the three countries shows that human rights violations on the basis of HIV sero-status are rarely reported to the authorities. Out of the three countries, Kenya had the highest number of unreported violations (68.2%) followed by Zambia with 42.8%. Kenya and Nigeria had a few respondents who indicated that they were yet to report to the authorities. The number of non responses was particularly high among the respondents in Zambia: about 7% of the respondents did not provide a response as shown in the figure below.

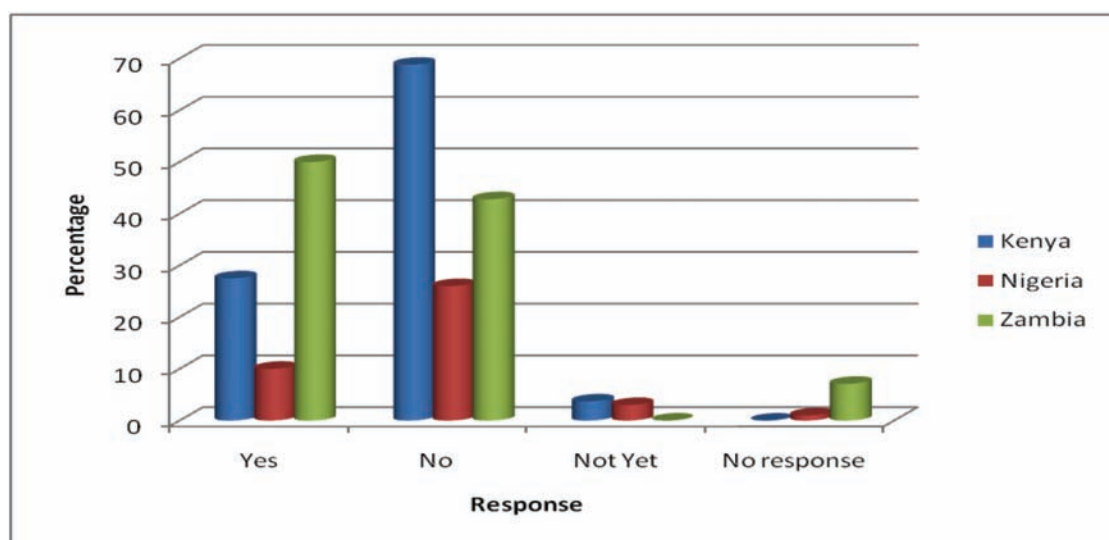


Figure 2: Percentage of violations reported to authorities

Respondents who had not reported their cases to the authorities were asked to state their reasons. The responses that were given provided generated useful information regarding the barriers faced by the respondents. Table 1 below shows that lack of awareness of their rights and fear are some of the underlying causes for the high proportion of rights abuses that were not reported. In two cases, respondents sought redress in the courts of law, won and were awarded damages.

The adverse effect of HIV-related stigma and discrimination on the uptake of services is highlighted by a male respondent from Kenya who stated that he did not report the violation because doing so would expose his HIV positive status. Not surprisingly, the fear of having a relative arrested came up among the reasons for the non-reporting of violations perpetrated within household setting. The results also demonstrate that PLHIV employ various coping strategies to deal with rights abuses. PLHIV networks, support groups and NGOs providing HIV services were frequently mentioned among places where from where respondents sought assistance.

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**Table 1: Reasons for not reporting rights violations**

Reason for not reporting violation	Country		
	Kenya (n=53)	Nigeria (n=40)	Zambia (n=29)
Afraid	13%	36%	-
Did not know that I could report it	13%	5%	46%
I was not able to	4%	5%	-
Did not know who to report to	10%	18%	30%
I dealt with it and did not matter anymore	2%	2%	15%

*Note: Multiple answers given and not all responses presented*


### 3. Human rights violations often result in a combination of psychological, economic and social consequences for PLHIV

Respondents were asked to report on how the violations they reported had impacted their lives. Results from the pooled sample show that more than 80% of the respondents indicated that the human rights violations they had experienced had affected them in several ways. Most of the respondents narrated how they had suffered psychologically, socially and economically as a result of the rights violations. Stress, shock, depression, fear and loss of self esteem and other similar conditions were specifically mentioned by those who reported having suffered psychologically. The following accounts provide insight into the experiences documented in the three countries:

*“After being diagnosed and found HIV positive by the health authority my husband sent me away from our matrimonial home.” (Female PLHIV, Kenya)*

*“... I lost my job and my wife deserted me while in Luanshya (town in Zambia) and admitted in the hospital. She hired a vehicle and collected all goods and said we were shifting to a bigger house...After the loss of employment due to my sickness, I had no money and had to sell the remained properties.” (Male PLHIV, Zambia )*

*“My church would not wed any member unless the person takes an HIV test and it is certified negative. When I was planning to get married, I went for an HIV test. My test result was positive and that automatically ended my marriage as my fiancée told me we could no longer go ahead... Everybody was keeping away from me and that made my commercial enterprise/business to collapse. I couldn't take part in social gatherings.” (Male PLHIV, Nigeria)*



Among the respondents who reported suffering economically, this was often associated with the loss of a job and consequently regular income. Respondents also narrated how they could not continue with business as people did not want to buy from them or lost their late husbands' wealth such as benefits and land. A victim's relative reported that his uncle was dismissed from serving as a pastor in his church when he tested HIV positive in 2008. Since he was mostly depended on the church for sustenance, he became financially unstable and sold his rural house in order to support his family.

#### 4. For women living with HIV, human rights abuses tend to exacerbate existing inequality due to gender and cultural practices

Even in countries with generalised HIV epidemics, vulnerable groups are often most affected by HIV and AIDS. For various reasons, they may be more at risk of becoming infected. The same factors that increase their vulnerability to HIV infection are often responsible for multiplying the barriers to care, treatment and support once they are infected. As a vulnerable group, women living with HIV encounter blame and abuse, and as the experiences of some of the pregnant respondents demonstrate, a visit to a health facility while pregnant can trigger scorn and recrimination from health care workers.

One area of interest which the study sought to explore is variation in human rights abuses among different vulnerable groups. In this regard, all respondents were asked to indicate which vulnerable groups they identified with from a selection that included pregnant woman, disabled gay/lesbian, sex worker, injecting drug user and migrant. However, the number of respondents in these vulnerable groups was not large enough to allow for any meaningful comparisons between groups. For instance, only one respondent identified himself as an injecting drug user and the pooled sample had only one adolescent respondent.

Overall, the samples drawn in the three countries were dominated by women except in Zambia where the two sexes were evenly represented as illustrated in figure 3 below. Although women are disproportionately affected by the HIV epidemic in all the three countries, the sex distribution could be a result of women being generally more willing to share their experiences compared to men.

# Human Rights Count!

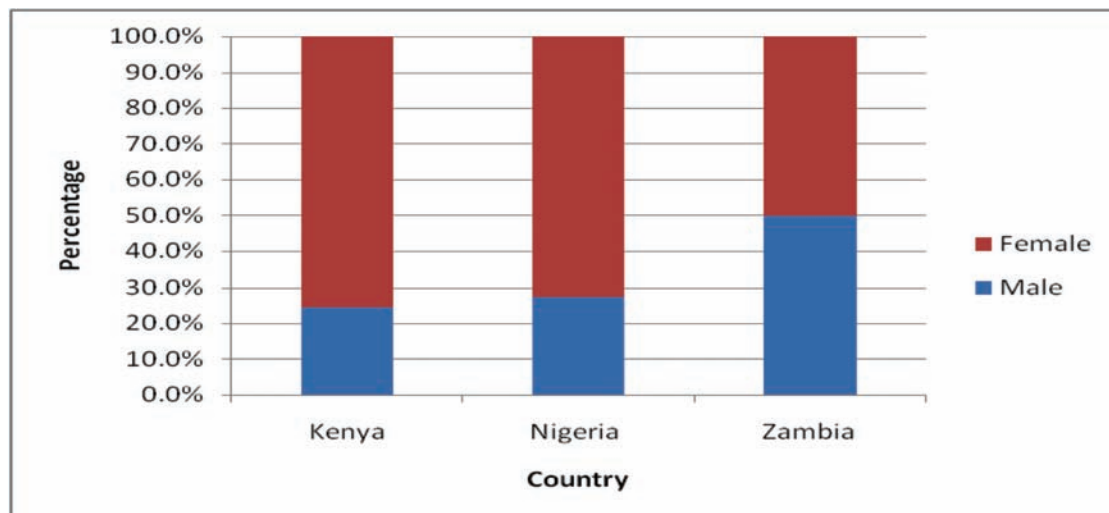


Figure 3: Sex distribution

The qualitative analysis of the results reveals evidence of gender inequality rooted in women's social, economic and sexual subordination enshrined in social norms and culture in the three countries surveyed. Where laws and custom limit women's ability to inherit property from their spouses, widowhood or divorce were often associated with destitution.

One HIV positive woman in Zambia narrated how her husband occasionally refused to give her transport money to enable her collect medication. A female respondent in Nigeria gave the following account:

*"After my husband's burial and funeral, my late husband relations came to me and told me to go back to my father's house. They told me to my face to go home to my people "you will soon die of the ailment that killed your husband". They refused me taking anything belonging to their brother (my husband) including my sewing machine and other important properties of mine... They isolated, rejected and ejected me from their family."(PLHIV, female)*



## Conclusion and recommendations

From the forgoing, it is evident that addressing HIV related rights violations is inextricably linked to challenging the stigma and discrimination associated with being HIV positive. As noted by UNAIDS<sup>1</sup>, confronting stigma and discrimination is a prerequisite for effective prevention, treatment, care and support. Discrimination on the grounds of one's HIV status constitutes a violation of human rights. The results of this study also demonstrate that discrimination targeted at PLHIV or those believed to be HIV-infected, leads to the violation of other human rights, such as the rights to health, privacy and freedom from inhuman, degrading treatment.

The predominance of work related violations is to a large extent, an indication of the investment still required around HIV mainstreaming in both the public and private sectors. The equally large proportion of respondents who did not report violations because they didn't know that such a violation had occurred or didn't know where to seek redress suggests that more effort should be channelled to raising awareness on human rights in the context of HIV and of increasing the availability of programmes that increase human rights and legal literacy. Furthermore, the reasons that respondents put forth for not reporting cases of rights violations show that the enactment of appropriate protective laws does not automatically translate into more PLHIV seeking redress in the courts of law. For this to happen, it is necessary for national institutions to assess the enforcement of laws and policies; identify barriers to accessing justice and develop a remedial plan of action in partnership with key stakeholders. Based on the findings, the following recommendations are made:

- Interventions that address stigma and discrimination within the family, community and institutional settings should be intensified;
- Governments and civil society organisations should be encouraged to incorporate human rights, gender and legal literacy campaigns in interventions for PLHIV;
- Networks of PLHIV and human rights organisations should advocate for the establishment of functional courts or tribunals to deal with HIV related abuses;

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<sup>1</sup> UNAIDS (2007), *Reducing HIV Stigma and Discrimination: a critical part of national AIDS programmes*. Geneva: Joint United Nations Programme on HIV/AIDS.



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- Partnership building should be encouraged and established between the human rights commissions and other related bodies and networks of PLHIV at national and local level;
- A detailed assessment of national policies and laws that impact positively or negatively on PLHIV should be done with the aim of identifying specific gaps, and recommending amendments and strategies for protection of rights.
- A follow up study with a bigger sample and wider geographical spread should be conducted to examine human rights violations among different vulnerable sub-groups of PLHIV.

**Notes:**



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