



GHANA **AIDS** COMMISSION



THE PEOPLE LIVING WITH HIV STIGMA INDEX

GHANA



People Living With HIV (PLHIV) Stigma Index Study

Ghana

NAP+

GHANA AIDS COMMISSION

UNAIDS

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The national HIV and AIDS Technical Support Plan (TSP) 2011-2013 included the conduct of the Stigma Index Study to provide comprehensive data on the extent of HIV-related stigma and discrimination among Persons Living with HIV (PLHIV). In pursuance of this, the Ghana AIDS Commission (GAC) contracted Management Strategies for Africa (MSA), an organization focused on research, monitoring and evaluation as well as institutional, organizational and management capacity development for health institutions across sub-Saharan Africa, to work with the National Network of Persons Living with HIV in Ghana, NAP+, a National Coordinator and an international consultant (both PLHIV) to conduct the Stigma Index Study ensuring the Greater Involvement of PLHIV (GIPA) in Ghana. The execution of this study was therefore led by the network of PLHIV in Ghana for PLHIV in Ghana. NAP+ Ghana is very proud of this role played as part of the efforts to address the need for hard evidence of the existence of stigma and discrimination against PLHIV in Ghana. We hope that the results of this survey will influence national policy and advocacy programmes that would improve the lives of persons living with HIV.

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1. *Mr. Kofi Amofa, Chairman of the Committee and President of NAP+*
2. *Mr. Girmay Haile, Co-Chair for the Committee and Country Coordinator for UNAIDS Ghana*
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21. *Mrs. Elsie Ayeh, Local Coordinator, PLHIV Stigma Index Study (SIS)*

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- | | | | |
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ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ARV	Antiretroviral
ART	Antiretroviral Treatment
CDC-Ghana	US Centers for Disease Control and Prevention – Ghana
CHRAJ	Commission on Human Rights and Administrative Justice
ETWG	Expanded Technical Working Group on HIV and AIDS
FGDs	Focused Group Discussions
GAC	Ghana AIDS Commission
GDHS	Ghana Demographic Health Survey
GIPA	Greater Involvement of PLHIV
GNP+	Global Network of People Living with HIV and AIDS
GSS	Ghana Statistical Services
HIV	Human Immuno-Deficiency Virus
HTC	HIV Testing and Counseling
ICW	International Community of Women Living with HIV and AIDS
IDA	International Development Association
IPPF	International Planned Parenthood Federation
KATH	Komfo Anokye Teaching Hospital
KP	Key Populations
LC	Local Coordinator
MARPS	Most-at-Risk populations
MARPs TWG	Most-at-Risk Populations Technical Working Group
MOGCSP	Ministry of Gender, Children and Social Protection
MICS	Multiple Indicator Cluster Survey
MIPA	Meaningful Involvement of Persons Living with HIV
MSA	Management Strategies for Africa
NACP	National AIDS Control Programme
NAP+ Ghana	National Network of Persons Living with HIV in Ghana
NETEWAG	Network of Teachers and Educational Workers in HIV and AIDS, Ghana
NGOs	Non-Governmental Organizations
NHIS	National Health Insurance Scheme
NSP	National HIV and AIDS Strategic Plan
OIs	Opportunistic Infections
OSC	Oversight Steering Committee
PLHIV	Persons Living with HIV
PMTCT	Prevention of Mother to Child Transmission
SRH	Sexual and Reproductive Health
SSA	Sub – Saharan Africa
STIs	Sexually Transmitted Infections
UN	United Nations
UNAIDS	United Nations Joint Programme on HIV and AIDS
USAID	United States Agency for International Development



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EXECUTIVE SUMMARY

Introduction

HIV and AIDS-related stigma and discrimination is a pervasive problem worldwide and People living with HIV (PLHIV) in Ghana, as elsewhere, face stigma and discrimination in a variety of contexts, including the household, community, workplace, and health care settings. Widespread stigma and discrimination toward PLHIV in the general population and those perceived to be infected have been recognized to act as barriers to seeking health services and uptake of HIV services including HIV Testing and Counselling (HTC), adherence to antiretroviral therapy and access to supportive services. Thus stigma attached to HIV, and the resulting discrimination is a critical barrier to achieving universal access to HIV related prevention, treatment, care and support.

The Ghana AIDS Commission (GAC) fully recognizes the potential threats that this social phenomenon poses to Ghana's quest to attain universal access towards achieving the health-related Millennium Development Goals and towards halving all new HIV infections by 2015. The national HIV and AIDS Technical Support Plan (TSP) 2011-2013 therefore included the conduct of the Stigma Index Study to provide comprehensive data on the extent of HIV-related stigma and discrimination among PLHIV.

The PLHIV Stigma Index is a joint initiative of global level organizations including The Global Network of People Living with HIV and AIDS (GNP+); The International Community of Women Living with HIV and AIDS (ICW); The International Planned Parenthood Federation (IPPF); and The Joint United Nations Programme on HIV and AIDS (UNAIDS) who have worked together since 2004 to develop this survey. The Stigma Index provides a tool that measures and detects changing trends in relation to stigma and discrimination as experienced by persons living with HIV. This study documents the various experiences of HIV-related stigma and discrimination against PLHIV and in so doing; contributes to strengthening evidence-informed advocacy, policy change and programmatic interventions.

Objectives of the study

The aim of the study was to collect information on stigma and discrimination against persons living with HIV (PLHIV) and key populations which serve as barriers to the uptake of HIV services by PLHIV and key populations and elicit information on the violation of rights of PLHIV that will help in advocacy efforts with the specific objectives to:

- a. Document the various experiences of PLHIV (and key populations) on HIV related stigma and discrimination in Ghana
- b. Document mechanisms for reducing stigma and discrimination towards PLHIV and key populations
- c. Contribute to an evidence base for advocacy, policy change and programmatic interventions to address HIV-related stigma and discrimination

Methodology

The study was a nationwide, cross sectional mixed methods study conducted in line with the requirements and guidelines for the People Living with HIV Stigma Index using standardized research tools and the stepwise process described in the Stigma Index Study User Guide (available at www.stigmaindex.org).

The study was overseen by the Oversight Committee (OSC) made up of Network for People Living with HIV (NAP+), Network of Teachers and Educational Workers in HIV and AIDS, Ghana (NETEWAG), Ghana AIDS Commission (GAC), National AIDS Control Programme (NACP), National Anti-stigma and Discrimination Technical Working group, the Expanded Technical Working Group on HIV and AIDS (ETWG), the Most at Risk Technical Working group (MARPs, TWG), Commission for Human Rights and Administrative Justice (CHRAJ), UNAIDS and Civil Society Organizations. NAP+ led the execution of this study with support from three local consultants with expertise and extended experience in social research with PLHIV and key populations in collaboration with a Local Coordinator and international consultant, both PLHIV. In order to improve execution of its mandate and ensure that NAP+ reaches its constituencies and ensures their effective involvement in line with the Greater Involvement of PLHIV (GIPA) and Meaningful Involvement of PLHIV (MIPA) principle, the Oversight



Committee (OSC) of the PLHIV Stigma Index Study established a Technical Working Group, to work with the consultants to ensure the technical soundness of the Study.

The Study population was all made up of PLHIV in Ghana. There are over 235, 982 persons living with HIV and AIDS in Ghana (NACP, 2013) some of whom are organized into support groups with membership in all the ten regions of the country. Through a combination of purposive and simple random sampling methods, 427 PLHIV were selected from 78 ART sites in rural and urban locations in all the ten regions of the country to participate as respondents/interviewees for the study. The number of PLHIV that were interviewed in each region was proportionate to the number of PLHIV within the region. Though key populations living with HIV were not purposively targeted for the interviews, the random sampling of respondents was aimed at reaching some of them.

Field work was conducted between 10-15 days within 10th to 28th February 2014, by 28 trained Research Assistants purposively selected from among NAP+ and NETEWAG by a rigorous screening process. Among these were six (6) supervisors distributed across the 10 regions of the country who also assisted in the conduct of 6 focus group discussions (FGDs) from three selected geographic zones (coastal, middle/forest and savanna zones) and interviews to record case studies from among the respondents.

Quantitative data was entered and analyzed using SPSS and various frequencies and levels of analysis were carried out as per the guidelines for data analysis by the headquarters of the Stigma Index Study (SIS HQ). Qualitative interviews were recorded, transcribed verbatim and themes depicting the experiences of the PLHIV, their perceptions about stigma and discrimination were used to re-enforce the results from the quantitative data.

An overall Stigma and Discrimination Index (S&DI) was calculated using 33 indicators grouped into 7 categories each of which included a composite of stigma indicators corresponding to the defined categories. The 7 broad categories used were Exclusion, Access to work, health and education, feelings of the PLHIV respondents because of their HIV status, things the PLHIV are fearful of because of their status, knowledge of international and national laws and policies that protect their rights, reasons why the PLHIV did not try to get a legal redress for rights abused as well as issues about disclosure.

Limitations of the study

Though the Ghana PLHIV Stigma Index Study has been successfully carried out, it was not without limitations and challenges.

Due to instructions from the Stigma Index User Guide, the research team agreed not to change anything in the questionnaire but FGDs were used to capture some of the in-depth descriptions of the country specific dimensions of stigma against PLHIV that could not be captured with the questionnaire.

Calculating the household income was also challenging because some of the respondents get their food supply from their farms and other donations in kind from benevolent relatives which could not be quantified into exact monetary values. Those interviewees/respondents who were not bread winners/ household heads could not give the exact estimates of the household income hence the household income levels of some of the respondents may not be the exact reflection of the true situation.

However since the calculation of the sample size took into account all such possible errors and possible deviations, the research team is confident that these limitations did not affect the results of the study.

Summary of the results of the study

A. Socio-Demographic characteristics of Respondents

1. The sex distribution of respondents drawn from all the ten regions reflected the gendered nature of HIV prevalence nationwide, having featured a much higher proportion of female respondents (71.4%, n=305) than males (28.6%, n=122).
2. More than 1 in 10 of the respondents belonged to key populations (KP) especially men who have sex with men (MSM) and Gay/lesbian or sex worker.
3. With regard to age distribution, respondents were mostly aged between 30 and 50 years. Experiences of PLHIV below 15 years were not captured due to the particular study design. However, the significant presence of 38 AIDS orphans



in PLHIV households was recorded, especially in urban areas, where they constituted almost two-thirds of the total. None of the key population respondents was below 20 years.

4. About half (51.6%, $n=220$) of the general PLHIV respondents and 42% ($n=21$) of PLHIV in key populations have been living with HIV for less than 5 years. However at least, one in every ten PLHIV interviewed had been living with the condition for 10 years, which sheds light on the country's successful management of HIV through sustained access to ARVs among others resulting in more people living longer, healthier and positive lives with HIV.
5. A total of 49.8% ($n=211$) and 50.2% ($n=213$) of the respondents were from rural and urban locations respectively with more proportions of the females (51.5%, $n=156$) residing in the rural locations than their male counterparts. Thus no significant rural-urban differentiation in terms of the residence of the PLHIV respondents, an indication perhaps, of the effectiveness of the nationwide spread of the ARV treatment and support services. However more than half of the KP PLHIV interviewed (65.3%, $n=33$) resided in urban locations.
6. Analysis of PLHIV relationship status revealed striking patterns of more than half of the respondents being in some form of a relationship. The qualitative information revealed intra-PLHIV marriage among majority of the respondents. Nevertheless, a total proportion of 15.9% of respondents had experienced separation or divorce.
7. About 81% ($n=347$) of the respondents said they were currently sexually active with more proportion of males (86.1%, $n=105$) than females (79.3%, $n=242$) being sexually active.
8. Only a third (33%, $n=140$) of the PLHIV interviewed had secondary level education or above. The lower levels of formal educational attainment observed among majority of the PLHIV interviewed accords with the general trend among PLHIV in Ghana. However most of the respondents belonging to KP had attained primary or higher level of education.
9. About a fifth (20.8%, $n=89$) of the respondents were unemployed, with higher levels of unemployment among the female (25.6%, $n=75$) respondents. About a third (32.8%, $n=132$) of the respondents were among the lower income group earning barely the minimum daily wage. However, despite the relatively low socio-economic status observed among respondents in general very minimal trends of food insecurity were reported. Food insecurity was more among the urban PLHIV and those who belonged to key populations.

B. Experiences with stigma and discrimination

1. The PLHIV respondents avoided all the forms of social exclusion and other forms of discrimination through non-disclosure of their HIV status to individuals and groups outside the health care delivery system with striking majority of respondents, above 85% ($n=366$) on the average, reporting they had "never experienced" any form of HIV-related social exclusion during the 12 months preceding the survey. The worst forms of stigma experienced by the respondents however were gossip and verbal insults or harassment, which featured an average of 63% and 79% respectively of the total cases of discrimination reported. More than one third of respondents experienced these forms of social exclusion at least once regardless of their socio-economic status or gender. Exclusion from religious activities was the least form of social exclusion experienced by the respondents due to lack of disclosure with only 6.6% of respondents having disclosed their status within their religious cycles.
2. Experience of stigma and discrimination was generally observed to be more prevalent among PLHIV in rural than in urban locations. There were also higher levels of stigma against key populations than other PLHIV across all the types and indicators of stigma analyzed. Experience of social exclusion among key populations exceeded that of the general PLHIV community by well over 100% on the average, and tended to occur in a more intensified form such as exclusion from social gatherings, family activities and to a greater extent from religious activities, in addition to experience of physical assault. Both the quantitative and qualitative findings attested to this. Thus the relatively higher vulnerability of key populations also surfaced in relation to all the forms of social exclusion.
3. More proportion of PLHIV respondents who were members of PLHIV network/support group experienced discrimination from their peers than those who were not members. PLHIV who did not belong to key populations also tended to inflict considerable emotional and psychological distress on PLHIV in key populations especially those with homosexual orientations. Non-HIV positive MSM also highly stigmatized members of their community who had tested positive affecting their access to services.
4. Respondents with no formal or just primary level education reported as much as 66.3% of all the reported cases of social exclusion. The highest income groups however reportedly experienced more levels of stigma and its associated forms of social exclusion than the lowest and middle income groups.



5. *Low educational attainment appeared to be inversely correlated with experience of physical assault among PLHIV in general. The worst perpetrators of physical assault were members of the households other than the spouses of the respondents. Whilst experience of physical assault in all contexts was higher among females, experience of psychological pressure and manipulation by spouses or partners featured a higher proportion of males than females. Respondents with no form of formal education were the least to experience psychological pressure and manipulation by spouses or partners.*
6. *A great deal of the self or internal stigma experienced by majority of PLHIV bordered on lingering fear and assumptions about being the target of public gossip, which together with verbal abuse/assault or harassment emerged as fundamental among PLHIV in general and MSM as well as women in particular.*
7. *Experience of stigma associated with poor nutritional and health status and pre-existing stigma does exist within PLHIV networks and tends to hinder access to social and emotional support for those affected, including MSM.*
8. *As much as 86% of the reasons for the experiences of social exclusion were either because of HIV status or both HIV status and another reason. The perceived reason why the respondents think they are being stigmatized given by almost a quarter of them was that people are afraid of being infected through casual contact. Religious beliefs and moral judgments were the least mentioned reason.*
9. *Overall, PLHIV attributed the persistence of stigma and discrimination to ignorance among the general public and inadequate information to transform the effects of the initial negative publicity that engendered fear of being HIV positive.*

C. Access to work, health and education

1. *Experience of discrimination in the contexts of housing, employment, education and healthcare exists, though relatively low on the average, as noted in respect of social exclusion. PLHIV attributed these to weak enforcement of policies, and likewise to PLHIV ignorance about the existing policies.*
2. *About a tenth of the respondents reported they had either been forced to change their place of residence or been unable to rent accommodation at least once in the last 12 months due to their HIV status. This was experienced more among those with urban residence.*
3. *Sixty nine (16.2%) said they lost their jobs at least once in the last 12 months because of their HIV status. Some of the participants of FGDs said they lost their sources of income because someone went to disclose their status to their clients who stopped patronizing their trade.*
4. *Dismissal from educational institution and denial of family planning, reproductive health services and health service in general was very minimal. Three of the respondents indicated that they had been suspended or dismissed at least once from an educational institution because of their HIV status in the last 12 months; three said their child/children had had such an experience and six said they had been denied health services because of their HIV status within the same period. Thirteen and five of the respondents said they had been denied family planning and sexual and reproductive health services respectively in the last 12 months*

D. Internalized stigma

1. *Unlike social exclusion, which majority of PLHIV had not experienced during the preceding year, experience of internal stigma, in the form of self-blame and fear of stigma, was more pervasive among respondents. Support group membership helped to mitigate the experience of internal stigma in respect of self-blame, but not in the case of fear of stigma.*
2. *A great deal of the self or internal stigma experienced by majority of PLHIV bordered on lingering paranoia about being the target of public gossip, which together with verbal abuse/assault or harassment emerged as a fundamental concern among PLHIV in general and MSM as well as women in particular.*
3. *Apart from the negative feelings associated with their HIV status, respondents also reported changes in their behaviours especially with regards to the decision not to have more children (40.8%, n=168) and not to get married (24.9%, n=104). These two decisions also ranked highest among the KP.*



E. Rights, laws and policies

1. Though knowledge levels about the Declaration of Commitment on HIV and AIDS as well as National HIV and STI Policy were moderate (41.9%, n=179 and 32.4%, n=135 respectively) there are still high levels of ignorance about the rights of PLHIV and the policies which work to their benefits. However, the female proportion exceeded that of males in this regard.
2. About a fifth of the respondents reported the abuse of their rights as persons living with HIV in the last 12 months and as much as three quarters of them did not seek redress for the abused rights. The reasons were mostly because they had insufficient financial resources to take action were advised by someone against taking action, had little or no confidence in the process or thought the process appeared too bureaucratic.
3. Institutions contacted by PLHIV for redress against their rights abused often provided support. However, the protection of the rights of PLHIV at the community level is woefully inadequate. Knowledge and awareness of the existence of rights, laws and policies among PLHIV might not necessarily translate into application.

F. HIV testing and diagnosis

1. The dominant reasons for testing were referral due to suspected HIV-related symptoms or illness/death of a spouse/partner or a family member. Few cases of involuntary testing and diagnosis were reported.
2. The level of personally initiated HIV testing was higher in urban (80%, n=36) than rural areas. Majority of the respondents (65.7%, n=276) voluntarily took the decision to be tested. This is encouraging and may be a pointer to the rigorous campaign for people to know their status. However the data collected also showed that 11% of respondents were coerced into taking the test and close to 16% were tested without knowing it.
3. It was evident from the trends captured in the data that about half of the respondents (50.6%, n=215), received both pre- and post- HIV test counselling; while the rest received only one-time counseling, either before (4.2%, n=18) or after (30.8%, n=131) testing; in addition to 14.4% (n=61) who received no counselling at all.
4. Low prevalence of stigma and discrimination associated with testing and diagnoses and this was reported to be indirectly associated with improved medical services for PLHIV; however, shortage of logistics was reported

G. Disclosure and confidentiality

1. The respondents in most cases feared the consequences of disclosure and hence tended to conceal their status from people within their social circles. Strategic disclosure of HIV positive status by PLHIV to health care providers and a few 'trusted persons' such as other PLHIV, through effective PLHIV and care-provider collaboration, was very high.
2. About 8% (n= 32) of the respondents confirmed that their health professionals disclosed their status to others without their prior consent.
3. A higher proportion of male respondents (50.0%, n=60) disclosed their status to their partners than the females (42.8%, n=128)
4. Disclosure to health and social workers engendered more supportive than discriminating reactions. Discriminatory reactions to HIV status disclosure were generally low among family members (8.1%, n=34) and spouses (6.9%, n=29) despite low level of disclosure in this context.

H. Treatment

1. Respondents had a good perception about their health condition as an overwhelmingly 95.3% (n=407) rated their health conditions as good, very good or excellent. A pointer to the high access to ARVs and treatments for OIs from the country's successful ART programmes especially with the NHIS registering all PLHIV.
2. Perceived access to ARVs and medication of OIs was almost universal. While 95.1%, (n=404) of PLHIV are on ART, a proportion less than 2/3 of males and a little over 2/3 of female, are on medication for OIs.
3. Drug stock-outs and the attempt to avoid stigmatization in their local communities make some PLHIV incur additional travel costs to treatment centers.
4. More than two thirds of the respondent (66.7%, n=284) said they had had discussions with a health worker on HIV related treatment options in the last 12 months.



I. Having children

1. *Although post-testing counselling about reproductive health options for PLHIV is currently high, almost one-in-ten of the respondents reported that their ARV treatment was conditioned on use of certain forms of contraception.*
2. *7% (n=29) said they were advised by a health professional not to have children after being diagnosed as HIV positive.*
3. *One hundred and six of the females said they received ART to prevent mother to child transmission when they were pregnant and 7.6% (n=27) of the total respondents said they had HIV positive child/children.*

J. Effecting change

1. *Consistent with the tendency to keep their HIV status from people in their social circles and the relative low exposure to external stigma and discrimination 77% (n=328) said they had never confronted, challenged or educated anyone who stigmatized or discriminated against them.*
2. *With almost 80% (n= 58) of PLHIV whose rights were abused in the last 12 months preceding the study avoiding engagement with issues affecting their rights in order not to attract public attention, the prospect of effecting change would be challenging.*
3. *The evidence suggests that the limited initiatives taken by PLHIV to confront stigma and discrimination, achieved positive results. PLHIV networks and support groups featured prominently in this context; and despite relatively low levels of disclosure to religious leaders reported by PLHIV, over 2/3 of those who confronted stigma, channeled their grievances through faith-based organizations.*
4. *Overall 63.7% (n=272) of the respondents supported other PLHIV and the main forms of support were emotional and support for referral services. The roles being played by 'Models of Hope' in making newly infected persons overcome suicidal tendencies and instilling hope into their other peers was highly recommended by the participants of the FGDs.*

Recommendations

The evidence from the study underscores the fact that PLHIV across the country persistently experience varying forms of stigma and discrimination. Due to a combination of several factors driving these two phenomenon including existing structural factors and social norms, effecting change would require concerted efforts by policy makers, programme managers, service providers, human rights organizations, community leaders, family members and religious leaders as well as active involvement of PLHIV networks to achieve lasting outcomes. The recommendations based on the concluding findings are therefore to draw the attention of policy makers and law enforcement agencies of Ghana, the Ghana AIDS Commission (GAC), the Ghana Health Services (GHS) and National AIDS Control Programme (NACP), NAP+ as well as Civil Society Organizations (CSOs) involved with PLHIV to specific actions they need to take in order to achieve a stigma and discrimination free society.

One key recommendation for all stakeholders is the importance to use the results and information from this study for programming, advocacy efforts and other activities geared at reducing stigma and discrimination against PLHIV so the gains achieved over time can be easily tracked and measured. It might also be insightful to explore the stigma-related experiences of younger and adolescent PLHIV in future studies in the face of the successful ART programmes in the country.

Due to the success of the treatment programme, in increasing the life expectancy for PLHIV, it is very important for development partners, donors and funding agencies not to relent in releasing funding to support the programme so that PLHIV can live healthy and positively.



Policy makers and law enforcement agencies

- » Urgently strengthen and enforce policies and legislation to address all the pockets of the forms of stigma and discrimination against PLHIV. These policies that work to the benefits of PLHIV (especially the National HIV and STI Policy) also need to be disseminated urgently among all PLHIV in order for them to be aware of their existence. This would also enable PLHIV to be aware of their rights as persons living with HIV. However the effective dissemination of the National HIV and AIDS policy should be more widespread and should not only target PLHIV networks but also the general public, including educational institutions. The policy document could be reduced to pocket sized abridged versions translated into the local languages and with pictures to depict the information so it can easily be understood even by those with no formal education and those that are not literate.
- » Ensure the increased participation of PLHIV from all levels in general and the grassroots in particular in the development of future policies and laws that are intended to benefit PLHIV to foster better ownership of those policies by PLHIV.
- » Reduce the time and cost involved in the processes in addressing reported cases of abuse in order to increase the confidence of PLHIV in the system so they can access the services in times when their rights are abused.
- » Educate formal and non-formal employees on the existing national workplace policy for them to comply and the policy needs to be enforced to ensure PLHIV don't suffer loss of their jobs and sources of income on account of their HIV status.
- » Clearly define the rights of PLHIV to decent accommodation in the national housing policy and this must be made known to landlords/landladies as well as the PLHIV community. Enforcement of these guidelines and policies should be constantly monitored by the rent control board of the nation.
- » Increase efforts on prevention and management of gender-based violence, legal reform and enforcement of laws and mechanisms protecting PLHIV in particular from gender-based violence, harassment etc.

Ghana AIDS Commission (GAC)

- » To control new infections among the general population and key populations in particular GAC should sustain its programmes on prevention using effective behavior change communication strategies that have proven to be effective in targeting the general population and non-HIV positive key populations, especially MSM and sex workers.
- » Advocacy strategies should underscore the fact that at least one in every ten PLHIV has survived the condition for a decade. A documentary dubbed "A decade with HIV" could therefore be developed to show-case the success stories of effective HIV treatment in Ghana. This will also enhance mobilization of funds locally to sustain access to ARVs as well as putting a positive face to being positive with HIV to disabuse the minds of the populace from the initial fear associated with being HIV positive. This will help reduce to a great extent the stigma and discrimination against PLHIV in society and also encourage more people to voluntarily take the test to know their status and PLHIV to disclose their status.
- » Avoid shortage of ARVs, testing kits and logistics for determining CD4 count as much as possible since this creates a lot of panic amongst PLHIV especially when they have to be referred to other facilities to access these services due to fear of being stigmatized or discriminated. In this regard the President's effort to ensure adequate and constant supply of the ARVs in the country by providing local pharmaceutical companies with the funding to commence local production of the drugs is highly commended.
- » The existence of some level of food insecurity among PLHIV is very alarming therefore programs that provide food supplements need to be continued and measures should be put in place to ensure their sustainability.
- » Interventions targeting PLHIV should factor in their low literacy and income levels; and as much as possible, programmes should be designed to ensure minimal cost to PLHIV. Though food insecurity was not too high the existence of some level of food insecurity among PLHIV is very alarming and programmes that provide food supplements need to be continued to support the group of PLHIV who have challenges in providing adequate food supply for their households. This will help improve the nutritional status of the affected PLHIV in order not for them to appear lean to attract any form of stigma and discrimination from the society in general or from their peers in particular.



- » Strengthen the “Models of Hope” concept through provision of logistics e.g. support to cover the cost of transportation to and from the ART sites and material incentives to motivate them to continuously provide the needed moral and psychosocial support to their peers especially those newly diagnosed so they would overcome their internal fears.
- » Include HIV-related stigma and discrimination indicators as part of the M&E system in the national HIV response to monitor and evaluate progress over time.

Ministry of Health, Ghana Health Services and National AIDS Control Program (NACP)

- » Ensure access, availability, sustainability, and quality of treatment and care services (e.g. availability and access to timely and appropriate antiretroviral therapy, diagnosis and treatment for Hepatitis B and Cervical and Prostate cancer screening).
- » Ensure access, availability, sustainability, and quality assurance of psychosocial well-being services (e.g. mental and emotional health services, counselling services and support groups).
- » Sustain the campaign for people to know their status however health workers that perform the test should be constantly monitored to ensure they adhere to the guidelines by providing proper pre- and post- test counseling. Sustained supply of testing kits to regional and district hospitals is very critical in this regard since the absence of the kits is resulting to only diagnostic testing defeating the success chalked by the “know your status” campaign.
- » Ensure confidentiality of HIV-positive status of PLHIV and provide friendly and enabling environment/conditions for safe, voluntary, and beneficial disclosure in order to encourage and increase the levels of strategic disclosure of HIV positive status by PLHIV to health care providers through effective PLHIV and care-provider collaboration. This may eventually evolve into PLHIV becoming more comfortable to disclosure to family members, friends, religious leaders and other possible ‘trusted persons’ in order for more PLHIV to receive support from their social circles.
- » Intensify public education in general and couples counselling in particular about the improved medical facilities available for HIV and AIDS management and the enhanced longevity for PLHIV. This would help reduce the rate of divorce especially among discordant couples and psychological pressure exerted on PLHIV in general by their spouses/partners.
- » Intensify education among the general public in general and PLHIV in particular (especially the males) about availability of PMTCT programme that has proven to be successful to address the high level of fear of having children among PLHIV.
- » Regularly evaluate, re-train and enhance the HIV management skills for health professionals especially those in low capacity areas. This is very critical to help improve their skills in providing non-judgmental, unprejudiced health quality health services in general and family planning, sexual and reproductive health services in particular to HIV positive clients.
- » Provide health-provider training on sexuality, gender, stigma, discrimination and gender-based violence
- » Uphold the Sexual and Reproductive Health rights of PLHIV by as much as possible actively involving them in reproductive decision making. Implement strategies to constructively engage men in reproductive and sexual health

NAP+ Ghana

- » Implement educational programmes within PLHIV networks and support groups on how important it is not to stigmatize against a peer PLHIV regardless of the physical appearance, economical status or sexual orientation to enable all PLHIV benefit from relevant support services.
- » Enhance access to psycho-social support by encouraging PLHIV to join a network or support group where their fears and feelings could be shared in order for them to get help from their peers who have gone through similar experiences but have been able to overcome and living positively. Build capacity of more PLHIV to provide psycho-social support to their peers
- » Increase advocacy efforts and empower PLHIV networks by improving their capacity to seek redress for rights abused. This would deter people from abusing the rights of PLHIV especially when they are made to face the law.



- » *Empower PLHIV to embrace and lead the meaningful involvement of people living with HIV in programmes and activities that concern PLHIV at all levels through:*
 - *positive leadership, participation in policy dialogue and advocacy*
 - *Mentoring of future leaders including women and young PLHIV*
 - *Peer support groups (adolescents and above 50's)*

Civil Society actors involved in the HIV response

- » *Build capacity of policy makers for policy monitoring and public accountability as well as the active involvement of all stakeholders in policy dialogue*
- » *Build advocacy capacity of organizations involved in PLHIV and networks of PLHIV to enable them to actively:*
 - *Campaign for policy change in areas where there are gaps*
 - *Mobilize the society and engage the community for social change*
 - *Mobilize resources for networks and associations of PLHIV to implement their activities*
 - *Facilitate networking opportunities*
 - *Link to other social justice and development movements or organisations*
- » *Educate and improve the literacy of PLHIV on Family planning, Legal and rights, building of self-esteem and confidence. Increase advocacy efforts and empower PL networks by improving their capacity to seek redress if their rights are abused*
- » *Engage in legal advocacy and activism for women's rights, rights for men who have sex with men and networking opportunities*
- » *Intensify education among the general public in general and PLHIV in particular (especially the males) about availability of PMTCT program that has proven to be successful to address the high level of fear of having children among PLHIV*
- » *Develop and implement age-appropriate and HIV-specific sex and relationships education for children and adolescents born with HIV.*
- » *The mere presence of some form of religious exclusion is indicative of the fact that there is still a lot of advocacy work to be done among religious leaders and the congregation to disabuse their minds from any negative moral behaviours associated with being HIV positive. Thus there is also the need to intensify efforts to build capacity of religious and traditional leaders for community mobilization and advocacy against all forms of social exclusion as well as strengthening solidarity among PLHIV for collective action.*
- » *Apart from spouses or partners of PLHIV, the next important groups to be targeted with anti-stigma related messages are members of PLHIV households who need to be educated on the need for them to provide the much needed emotional support for PLHIV.*



1.0 INTRODUCTION

1.1 Background

HIV and AIDS-related stigma and discrimination is a pervasive problem worldwide and People living with HIV (PLHIV) in Ghana, as elsewhere, face stigma and discrimination in a variety of contexts, including the household, community, workplace, and health care settings. Widespread stigma and discrimination toward PLHIV in the general population and those perceived to be infected have been recognized as barriers to seeking health services and uptake of HIV services including HIV Testing and Counselling (HTC), adherence to antiretroviral therapy and access to supportive services. Thus stigma attached to HIV, and the resulting discrimination is a critical barrier to achieving universal access to HIV related prevention, treatment, care and support.

The National HIV & AIDS Strategic Plan (NSP) 2011-2015 prioritized the identification of key drivers of stigma and the strengthening of capacity of networks, associations and support groups of Persons Living with HIV (PLHIV) on HIV related stigma. Although HIV-related stigma and discrimination is widely recognized as a barrier to accessing HIV prevention, treatment and care services in Ghana, there is no comprehensive data on the extent of the problem in Ghana. However anecdotal reports and previous studies on HIV-related stigma and discrimination in Ghana showed high levels of non-accepting attitudes among the general population and have provided some useful background data to guide the national HIV response. These include results on accepting attitudes towards PLHIV in the 2008 Ghana Demographic Health Survey (GDHS) and the 2009 study by GTZ/ReCHT in collaboration with GAC on “Stories on the experiences of PLHIV and survey on stigmatization towards high risk groups conducted in Tema and Accra”.¹

1.2 HIV and AIDS response in Ghana

Ghana's HIV prevalence is currently 1.37% of the estimated total population of about 24.7million (2010, Population and Housing Census), making the country one of those with low HIV prevalence globally. The HIV epidemic in Ghana continues to be a generalized epidemic though there are variations with geographic areas and certain populations (key populations). Described as a true leader in the fight against AIDS², new HIV infections have declined from 26,000 in 2002 to 8,000 in 2012³, while the adult prevalence rate dropped from 2.21% to 1.37% within the same period. The number of people accessing treatment for HIV and AIDS increased from virtually zero in 2002 to 2,300 in 2005, and 15,000 by 2012⁴.

This level of success has been made possible by the government's high level of commitment to fighting AIDS with the current president continuously and actively promoting the fight against AIDS, through published articles, updates to Parliament on the status of Ghana's AIDS epidemic and speeches to the Ghanaian people⁵. Ghana has also had a positive policy, advocacy and enabling socio-political environment for implementing a comprehensive multi-sectoral programme to combat the HIV epidemic with very strong planning efforts⁶ for more than a decade. The Ghana AIDS Commission established by an ACT of Parliament in 2002 as a supra-Ministerial Body with multi-sectoral representation has been coordinating the national response with the involvement of key Ministries, the private sector, traditional and religious leaders and civil society as well as persons living with HIV in the design, planning, implementation, monitoring and evaluation of programmes.

Through the various institutional arrangements such as the Partnership Forum, Technical Working Groups and decentralized structures such as the Regional and District AIDS Committees, and District Response Management Teams, the GAC interacts with all stakeholders and receives input and feedback towards the HIV and AIDS response and modifies priorities and interventions⁷. GAC brought together these key stakeholders to develop the National Strategic Frameworks on HIV and AIDS outlining clear targets on prevention, care and support, creating an enabling environment and quantitative targets that have been expanded upon in the second and third National Strategic Plans (2006–2010 and 2011–2015 respectively).

1 GTZ/ReCHT, 2009, “Stories on the experiences of PLHIV and survey on stigmatization towards high risk groups conducted in Tema and Accra”

2 The Beginning of the End, Tracking Global Commitments on AIDS Volume 2, The ONE Campaign Data Report 2013

3 Ibid

4 Ibid

5 Ibid

6 The Ghana Country AIDS Progress Report, Submitted to UNAIDS 2012

7 Ibid



Close partnerships with international aid mechanisms, particularly with the Global Fund, have also been crucial for the described largely successful AIDS response having received six grants for HIV and AIDS from the Global Fund since 2002. Other partners include USAID, DANIDA, CIDA, the International Development Association (IDA) and UN System⁸. Other programmes like the large-scale “Know Your Status” campaigns targeting to achieve almost universal awareness of HIV in Ghana as well as the eight-fold increase in number of PMTCT centres between 2005 and 2011, resulted in a dramatic reduction in new HIV infections in children due to the increased proportion of HIV-positive pregnant women receiving PMTCT treatment from 32% in 2009 to 95% in 2012, which add to the Ghana success story⁹. Ghana in 2013 emerged as the country that has achieved the greatest percentage reduction (76% since 2009) in new paediatric HIV infection and is optimistic of achieving the goal of virtual elimination before 2015¹⁰.

Though rightly hailed as a ‘success story’, the dynamics of the steadily tapering Ghanaian HIV epidemiological trends have not unfolded without challenges in respect of Stigma and Discrimination, among other formidable issues. In addition unlike most countries, Ghana has been comparatively slow to scale up ARV treatment. The ARV coverage rate of 58% is lower than the sub-Saharan African average of 62.5% coverage¹¹ and a unique challenge that hinders access to treatment is the country’s low medical clinic-to-patient ratio: (with only 0.1 physicians for every 1,000 people in 2010, compared with an African average of 2.3 per 1,000 people)¹². This is leading to high unmet need for ARVs and potential of reducing the survival of PLHIV and offsetting previous gains made

1.3 Stigma and Discrimination

HIV related stigma and discrimination is widely recognized as a barrier to accessing HIV prevention, treatment and care services. UNAIDS defines HIV-related stigma and discrimination as: “...a ‘process of devaluation’ of people either living with or associated with HIV and AIDS. Discrimination follows stigma and it is seen as the unfair and unjust treatment of an individual based on his or her real or perceived HIV status,” (UNAIDS, 2003). “Many people suffering from AIDS and not killed by the disease itself are killed by the stigma.” (Nelson Mandela, July 2002).

Peter Piot, the ex-UNAIDS Director and now director and professor at the London School of Hygiene and Tropical Medicine, in his keynote speech on “**the 10 myths about the HIV response**” during a convention organized by the International HIV and AIDS Alliance to mark its 20th anniversary said one of the myths is that “stigma and discrimination has disappeared now we have ART, and the promotion of human rights as part of the AIDS response is an unnecessary luxury which can be handled by others”¹³. Peter Piot included that “whilst many hoped that the introduction of effective treatment would mean ‘normalization of AIDS’, there is absolutely no evidence that this is the case. Everywhere you go you can still see the devastating impact of stigma and discrimination as a result of HIV.”

Globally, 34 million individuals are living with HIV; out of these 1.7 million HIV and AIDS related deaths have been recorded. Worldwide estimates suggest that 14.8 million persons living with HIV and AIDS are eligible for treatment; conversely only 8 million actually receive treatment. In Sub-Saharan Africa (SSA) 23.5 million people are living with HIV. However, out of this number about 7 million people are accessing HIV treatment (USAID, 2007). The role that stigma and discrimination has played to prevent people from undertaking HIV treatment cannot be overlooked. Cameron 2007 noted that if stigma and discrimination is not appreciated and made an intrinsic part of the national response, then none of the interventions any country adopts will be successful. He again mentioned that HIV and AIDS by far is the most stigmatized disease in history (Cameron, 2007). Also, from the late 1980’s to 2006, experts and communities have continuously identified HIV – related stigma and discrimination as a critical barrier to effectively controlling the epidemic. Stigma and discrimination operates at multiple levels throughout society: within individuals, families, communities as well as reflecting in government policies and practices (Heijnders, M. and van der Meij, S. 2006; Ogden, J. and Nyblade, L., 2005).

8 The Beginning of the End, Tracking Global Commitments on AIDS Volume 2, The ONE Campaign Data Report 2013

9 UNAIDS. 2013. “Global Report: UNAIDS report on the global AIDS epidemic 2013”. http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2013/gr2013/UNAIDS_Global_Report_2013_en.pdf (cited in The Beginning of the End. Tracking Global Commitments on AIDS Volume 2, The ONE Campaign Data Report 2013)

10 UNAIDS. 2013. “2013 Progress Report on the Global Plan” (as stated in The Beginning of the End. Tracking Global Commitments on AIDS Volume 2, The ONE Campaign Data Report 2013)

11 UNAIDS. 2013. “Global Report” (as cited in The Beginning of the End. Tracking Global Commitments on AIDS Volume 2, The ONE Campaign Data Report 2013)

12 “Rural practice preferences among medical students in Ghana: a discrete choice experiment”. <http://www.who.int/bulletin/volumes/88/5/09-072892/en/> (cited in The ONE Campaign Data Report 2013)

13 Peter Piot’s speech at the International HIV and AIDS Alliance’s 20th anniversary convention, themed around ‘Together to end AIDS’, <http://www.aidsalliance.org/NewsDetails.aspx?Id=291690>



1.3.1 Defining stigma and discrimination

Stigma, according to Goffman (1963), is “an attribute that is deeply discrediting” and that which invariably reduces a person or a group “from a whole and usual person to a tainted, discounted one”. Discrimination, therefore, is not conceptually considered separate from Stigma but considered the end result of the process of Stigma, in other words, “enacted” stigma. He further noted that by regarding “others” negatively, an individual or group confirms its own “normalcy” and legitimizes its devaluation of the “other.” Discrimination (or enacted stigma) is defined as “the negative acts that result from stigma and that serve to devalue and reduce the life chances of the stigmatized” (USAID 2005).

1.3.2 Types of stigma

Stigma is usually categorized into two main forms namely, External stigma: [the experience of individual treated differently by other people] and Internal stigma: [the way a person feels about himself or herself [e.g. shame, fear of rejection, discrimination]]. Also established within these broad categories are further classifications of Stigma including Physical Stigma, Social Stigma, Verbal Stigma and Institutionalized Stigma, all of which reflect the variable manifestations of stigma. People who are stigmatized often accept the norms and values that label them as having negative differences (Goffman, 1963). As a result, stigmatized individuals or groups may accept that they “deserve” to be treated poorly and unequally, making resistance to stigma and resulting discrimination even more difficult. This phenomenon is often termed “internalized stigma” (also sometimes termed “self-stigma”). Research shows that this internal stigma manifests in many ways, including self-hatred, self-isolation, and shame (Crandall 1991; Alonzo and Reynolds 1995; Lee et al. 2002 cited).

Basically, stigma works by producing and reproducing social structures of power, hierarchy, class and exclusion by **transforming differences into inequality**. Compound stigma (also referred to as multiple stigma), is HIV stigma that is based on pre-existing stigmas, frequently toward homosexuals, commercial sex workers, injecting drug users, women, and youth (Herek and Capitanio 1993; Herek et al. 2002; Boer and Emons 2004; Brown et al. 2004; Kalichman and Simbayi 2004; Nyblade 2004). Stigma however is not unique to HIV and AIDS. It has also been seen associated with tuberculosis, syphilis and leprosy. Likewise, its manifestation is generally evident in the context of diseases associated with transgression of social norms.

1.3.3 Understanding stigmatization and discrimination as social processes

Insights from Social and political theory help us to understand that stigmatization and discrimination are not isolated phenomena or the expression of individual attitudes, but are social processes used to create and maintain social control, to produce and reproduce social inequality. Stigma and Discrimination are used to create “difference” and social hierarchy. While this theoretical premise generally facilitates understanding of the twin concept of stigma and discrimination, in Ghana and elsewhere, it is also instructive to note that many people who discriminate against HIV positive people may be oblivious to how their attitudes and actions inadvertently foster unsafe behaviour among the general population as well as the psychological aspects of the phenomenon. This is even more evident in the Ghanaian populace where comprehensive knowledge about HIV prevention for women and men were as low as 33.8% and 39.1% respectively in the Ghana Multiple Indicator Cluster Survey (MICS) 2012¹⁴.

Previous studies on HIV-related stigma and discrimination in Ghana, such as the Ghana Demographic Health Survey (GDHS), the 2009 collaborative study by GTZ/ReCHT featuring “Stories on the experiences of PLHIV” and subsequent survey on stigma and discrimination against PLHIV and high risk groups conducted in Tema and Accra, as well as existing qualitative studies, reveal high levels of non-accepting and differentiating attitudes among the general population (e.g. 2009 AFWD sponsored Research on Gender norms, violence and HIV by the Gender Studies & Human Rights Documentation Centre). According to the Ghana Multiple Indicator Cluster Survey (MICS 2012), accepting attitudes towards persons living with HIV were as low as 6.3% and 15.2% for women and men respectively. These and many more local and international studies have underscored the complexity of the phenomenon citing a myriad of individual and systemic underpinnings.

1.4 Ghana’s efforts to reduce Stigma and Discrimination as part of the Response

Stigma and discrimination associated with HIV and AIDS go beyond PLHIV; it affects their families including caregivers, health workers providing HIV services and Most-At-Risk Populations (MARPS). Within families, the majority of caregivers for PLHIV are women who often face stigma and discrimination as they carry out their responsibility of care. The Ghana AIDS Commission (GAC) fully recognizes the potential threats that this social phenomenon poses to Ghana’s quest to attain universal access, towards achieving the health-related Millennium Development Goals and towards halving all new

¹⁴ The Ghana Multiple Indicator Cluster Survey (MICS) 2012



HIV infections by 2015. This reality is further compounded by existing gaps in the legal and policy environment, on issues of stigma and discrimination against persons living with HIV (PLHIV) and most-at-risk populations (MARP) which hinder progress.

As part of its national response, the GAC has, since 2002, undertaken a number of interventions to mitigate HIV-related stigma and discrimination, based increasingly, on recognition of the need for a multi-faceted approach and for periodic review and exploration of novel approaches. The GAC's commitment to this course is reflected, for example, in its partnership with law enforcement agencies and the judiciary, and its engagement with the Constitutional Review Committee in 2010, to ensure that adequate constitutional provisions are made for legal reforms, notably the quest for an HIV specific law to strengthen the legal environment related to HIV and AIDS in Ghana. The National HIV and STI Policy, for example, looked at thematic areas involved in alleviating the social, cultural and economic effects of HIV and AIDS, and STIs at all levels, to reduce HIV-related stigma and discrimination as well as address the impact of gender norms and stereotypes, the challenges faced by households and caregivers, and ensure equal access to basic needs for PLHIV, orphans and vulnerable children. The policy, therefore, seeks to mitigate stigma and discrimination, by ensuring adequate and accurate information, strengthening stakeholder commitment through a multi-sectoral advocacy approach, strengthening and utilizing legal and policy resources to support a rights-based response to HIV-related stigma and discrimination to address the fears, misconception and myths about HIV and AIDS.

Other related practical interventions include reinvigoration of the National anti-stigma and discrimination Technical Working Group to provide technical guidance to the Ghana AIDS Commission (GAC), the Expanded Technical Working Group on HIV and AIDS (ETWG), the Most-at-Risk Technical Working Group (MARPs TWG), CHRAJ and other stakeholders on HIV-stigma and discrimination related issues as well as the introduction of the "Heart-to-Heart Campaign" in 2011, to mitigate the negative impact of stigma and discrimination by putting a 'human face' to HIV through using HIV positive volunteers as 'Ambassadors' to drive the campaign, among others.

Some implementing partners including Ghana Centre for Democratic Development (CDD) and the SHARPER project with funding support from PEPFAR and the UN system have also jointly and severally built the capacity of CHRAJ, the criminal justice system, and the police, among many others, to better understand HIV and KP-related stigma and discrimination in the hope that PLHIV and KP whose human and legal rights are abused or violated can have access to justice. CHRAJ has also recently launched a website (www.drssystem@chraj.com) in efforts to facilitate reporting on these violations and abuses. Ghana AIDS Commission, Centres for Disease Control and Prevention (CDC) - Ghana, and other stakeholders have also held sensitization and advocacy interactions with senior government officials and parliamentarians on key HIV and AIDS issues including the need for HIV-specific legislation. The GAC together with other partners are also implementing the MARPS Strategy, the UNAIDS is also supporting Civil Society in these efforts as well as the collaboration with Human Rights Advocacy Centre (HRAC) to provide legal aid to PLHIV and key populations.

1.5 The National Network of Persons Living with HIV in Ghana, NAP+

The National Network of Persons Living with HIV in Ghana, (NAP+ Ghana), was established to contribute to the efforts to having Ghana as a country in which Persons Living with HIV (PLHIV) enjoy equal rights, opportunities and responsibilities as everyone else without any form of discrimination against them. The network was formed to provide the required structure and system for representing the views, hopes and aspirations of Persons Living with HIV and AIDS (PLHIV) across the country. The Network also aims to improve the quality of lives of persons with HIV through several strategies, including effective participation in national policy and programme dialogue, effective advocacy, capacity building and strengthening, information sharing and working together with partners in a coordinated manner.

The Ghana Network of Persons Living with HIV and AIDS (NAP+) is registered as a company limited by guarantee under the Ghana Company's code of 1963. The organization works in partnership with institutions such as Ghana AIDS Commission (GAC), Persons Living with HIV and AIDS (PLHIV) Associations and Support Groups, National AIDS Control Programme (NACP), United Nations Joint Programme on HIV and AIDS (UNAIDS), Care International's Prevent Project, Global Fund Round 8 Project with ADRA as well as USAID/FHI360/SHARPER Project.

NAP+ Ghana serves as the national umbrella body to direct, coordinate and provide a common voice for PLHIV in Ghana. The objectives of NAP+ Ghana according to the 2008 NAP+ constitution, are to facilitate and coordinate activities of Associations or Support Groups of persons living with HIV in Ghana; to facilitate the formation of support groups of PLHIV nationwide; to facilitate education, sharing of information, ideas, experiences and resources between and among members of NAP+ Ghana; to promote and support partnership building and strengthen alliances with relevant bodies and agencies working on HIV and AIDS related programs both nationally and internationally among PLHIV; to provide leadership and



a common forum for concerted advocacy efforts and for appropriate policies, legislation and human rights, including the right of PLHIV to healthcare and access to drugs for the treatment of infections etc.; to engage in empowerment and enterprise development activities that will improve the quality of life of PLHIV as well as to mobilize funds for care and support activities of member organizations at all levels.

Membership of NAP+ Ghana is open to Associations or Support Groups of Persons Living with HIV and AIDS. Such Associations or support groups are required to register with a district or regional branch of NAP+ Ghana, as the case may be and subscribe an annual commitment fee as determined by the National Executive Council. NAP+ currently has a total estimated nationwide membership of 270,000 PLHIV with about 350 member associations and support groups all over the nation. Some of the activities NAP+ has been undertaking include institutional capacity development to promote the principles of GIPA and document gender and human rights abuses/violence directed against PLHIV, production and publication of quarterly NAP+ Electronic Newsletter as well as SMS text messaging on positive living to PLHIV across the country.

‘MODELS OF HOPE’

In order to help surmount the problem of many PLHIV dying without hope due to rejection by family and friends and isolation, PLHIV described as ‘Models of Hope’, who have had various degrees of experiences because of the infection, have taken it upon themselves to provide care and support to their fellow PLHIV and give themselves and others hope. ‘Models of Hope’ therefore are role models to their peers in a supportive and encouraging environment that many don’t find within their families and home communities.

Through monthly sessions, ‘Models of Hope’ are instructed in providing comfort and coping mechanisms to others living with HIV and AIDS in one-on-one counselling sessions. In the clinics (ART sites) the ‘Models of Hope’ help their peers to pick their folders, prepare them to see the physicians, counsel them and help to identify their close relatives/friends to help them adhere to the counselling they received on antiretroviral therapy by taking their drugs religiously.

These peer educators also help to reduce the rate of infection in their communities by sharing accurate information about living with HIV and AIDS and maintaining a supportive network that resists stigmatization. They also help the health care providers to trace defaulters. What motivates them is the knowledge they have gained about HIV and AIDS and living positively, the good feeling of making clients happy and living positively with HIV as well as, helping them overcome self-stigma and discrimination. (Extract from Raphael Avornyo, 2013)

1.6 The PLHIV Stigma Index

The PLHIV Stigma Index is a joint initiative of global level organizations including The Global Network of People Living with HIV and AIDS (GNP+); The International Community of Women Living with HIV and AIDS (ICW); The International Planned Parenthood Federation (IPPF); and The Joint United Nations Programme on HIV and AIDS (UNAIDS) who have worked together since 2004 to develop this survey. The Stigma Index provides a tool that measures and detects changing trends in relation to stigma and discrimination as experienced by persons living with HIV. This study documents the various experiences of HIV-related stigma and discrimination against PLHIV and in so doing; contributes to strengthening evidence-informed advocacy, policy change and programmatic interventions.

The People Living with HIV Stigma Index Study also aims at gathering data and information using a tried and tested tool that will measure and detect changing trends in relation to stigma and discrimination experienced by persons living with HIV. The results of the Study is envisaged to inform better country policies related to HIV, ensure more effective programs to support the on-going implementation of the national response and be an empowering experience for the persons living with HIV involved in the process.

Policy and programme managers have long recognized that action is needed to address stigma and discrimination. The information gained from the Index will provide evidence for the success (or failures) of current programmes and highlight neglected areas requiring future action. These include improving workplace policies, informing debates about



the criminalization of HIV transmission, and promoting the realization of human rights. Consequently, the Index will be a powerful advocacy tool which will support the collective goal of Governments, NGOs and activists alike to reduce stigma and discrimination associated with HIV.

1.7 Objectives of the study

The aim of the study is to collect information on stigma and discrimination against persons living with HIV (PLHIV) and key populations which serve as barriers to the uptake of HIV services by PLHIV and key populations and elicit information on the violation of rights of PLHIV that will help in advocacy efforts with the specific objectives to:

- a. Document the various experiences of PLHIV (and key populations) on HIV related stigma and discrimination in Ghana
- b. Document mechanisms for reducing stigma and discrimination towards PLHIV and key populations
- c. Contribute to an evidence base for advocacy, policy change and programmatic interventions to address HIV-related stigma and discrimination

1.8 Study limitations

Though the Ghana PLHIV Stigma Index Study has been successfully carried out, it was not without limitations and challenges listed below.

The purposive selection of the ART sites closer to locations of the interviewers may have possibly resulted in the study missing out other PLs whose experiences and views may have enriched the study. Again there may be those PLHIV out there who know their status but are not openly accessing treatment at the ART sites whose experiences could therefore not be captured.

Due to instructions from the Stigma Index User Guide, the research team agreed to keep all questions as they are in the questionnaire but the FGDs were used to capture some of the country specific socio-cultural dimensions of stigma against PLHIV in Ghana that were not captured with the questionnaire. Despite efforts made to target some key populations through the FGDs, the study did not manage to collect in-depth information about sex workers and IDUs living with HIV.

The question about duration living with HIV has many interpretations, but for the purposes of this study it was agreed by the research team that the time the one first tested positive or diagnosed is the time to be used when asking that question.

Calculating the household income was also challenging because some of the respondents get their food supply from their farms and other donations in kind from benevolent relatives and hence could not quantify such income into exact monetary values. In addition to this, those interviewees/respondents who were not bread winners or household heads could not give the exact estimates of the household income hence the household income levels of some of the respondents may not be the exact reflection of the true situation.

However since the calculation of the sample size took into account all such possible errors and standard deviations, the researchers are confident that these limitations did not affect the results of the study.



2.0 METHODOLOGY

The study was a nationwide, cross sectional mixed methods study, and was conducted in line with the requirements and guidelines for the People Living with HIV Stigma Index using standardized research tools and the stepwise process described in the Stigma Index Study User Guide (available at www.stigmaindex.org). These tools and user guide were developed by persons living with HIV through an initiative of the founding partners working together since 2005, for persons living with HIV (PLHIV) to measure stigma and discrimination experienced by PLHIV.

The study was overseen by the Steering/Oversight Committee made up of Network for People Living with HIV (NAP+), Network of positive teachers (NETEWAG), Ghana AIDS Commission (GAC), National AIDS Control Programme (NACP), National Anti-stigma and Discrimination Technical Working group, the Expanded Technical Working Group on HIV and AIDS (ETWG), the Most at Risk Technical Working group (MARPs, TWG), Commission for Human Rights and Administrative Justice (CHRAJ), UNAIDS and Civil Society Organizations. NAP+ led the execution of this study with support from three local consultants with expertise and extended experience in social research with PLHIV and key populations in collaboration with a Local Coordinator and international consultant, both PLHIV.

In order to improve execution of its mandate and ensure that NAP+ reaches its constituencies and ensures their effective involvement in line with the GIPA and MIPA (Meaningful Involvement of PLHIV) principle, the Oversight Steering Committee (OSC) of the PLHIV Stigma Index Study established a Technical Working Group. This Working Group was assisted by the Local Coordinator (also a PLHIV) endorsed by the OSC to perform their functions by working with the consultants to ensure the technical soundness of the Study, reporting constantly to the OSC. Thus all the members of the research team worked together to ensure quality data was collected and entered, generated the data tables and compiled the findings and narrative report.

The Study population was all made up of PLHIV including KP living with HIV in Ghana. There are over 235, 982 persons living with HIV and AIDS in Ghana some of whom are organized into support groups with membership in all the ten regions of the country. Through a combination of purposive and simple random sampling methods, 427 PLHIV (sample size calculations described below) were selected from all the ten regions of the country to participate as respondents/interviewees for the study. The number of PLHIV that were interviewed in each region was proportionate to the number of PLHIV within the region.

The study was conducted in three phases, which are described in detail in the sessions below. Field work was conducted between 10-15 days by 28 trained Research Assistants purposively selected from among the NAP+ and Network of positive teachers (NETEWAG) by a rigorous screening process. Among these were six (6) supervisors distributed across the 10 regions of the country who also assisted in the conduct of focus group discussions (FGDs) and interviews to record case studies from among the respondents. Quantitative data was entered and analyzed using SPSS and various frequencies and levels of analysis were carried out as per the guidelines for data analysis by the International Partnership for the PLHIV Stigma Index Study. Qualitative interviews were recorded, transcribed verbatim and analyzed into themes depicting the experiences of the PLHIV, their perceptions about stigma and discrimination to re-enforce the results from the quantitative data.

2.1 Preparatory and planning phase:

This phase involved meetings with GAC, a desk review, guidance from PLHIV Stigma Index Coordinator (as required in the stigma index user guide), inception meeting with Oversight/Steering Committee, Selection of Interviewers, Sampling, Finalization of Instruments, as well as application for ethical clearance/approval for the study.

2.2 Desk review

A desk review of stigma and discrimination materials including previous studies as well as policy documents was carried out. These documents were sourced from the Ghana AIDS Commission, UNAIDS, the Ghana Health Service and Civil Society Organizations as well as legal bodies engaged in stigma and discrimination related activities within the country. The review of these documents and others provided the information and secondary data to assess the performance of the indicators; help identify gaps and also aid in documenting some of the challenges, successes, lessons learnt and best



practices in advocacy efforts towards reducing stigma and its associated discrimination against PLHIV in Ghana. The information also served as background and helped in defining the country context for the index to be assessed.

2.3 Guidance from Stigma Index Coordinator

As part of the first step in undertaking the study and upon agreement from GAC, the research team communicated with the international consultant who was part of the global team that pioneered the development and implementation of the study via the electronic media (emails). This was to seek guidance for the planning of the study and preparation for the training of the interviewers as well as the conduct of the field work. This consultation which was part of the requirement stated in the Stigma Index User Guidelines helped the local consultants to obtain information about challenges and lessons learned from other countries which have carried out the Stigma Index Study, to guide the Ghana study.

2.4 Inception meeting with Steering Committee

The Stigma Index User Guidelines also advise the need to set up an advisory committee. For this study, this body comprised existing groups that have initiated strategies and interventions as part of the country's response towards reduction of stigma and discrimination against PLHIV and key populations. These included NAP+ as chair, GAC and UNAIDS as co-chairs, NETEWAG, NACP, National Anti-stigma and Discrimination Technical Working group, the Expanded Technical Working Group on HIV and AIDS (ETWG), the Most at Risk Technical Working group (MARPs, TWG), (CHRAJ), and Civil Society Organizations. The inception meeting was part of the initial meetings to introduce to the committee the HIV Stigma Index research study, discuss how the research results would support local advocacy, possible dissemination strategy for the results, including sharing of the results with the study participants and the wider community and a mechanism whereby the members of the advisory committee would be kept informed about the progress of the research. Comments from the meeting were used to enrich the methodology to ensure the study was carried out in as much scientific manner as possible. Representatives from two research institutions, Ghana Statistical Service (GSS) and Institute of Social Statistics and Economic Research (ISSER) were also members of the Oversight Committee as per requirements of the study.

2.5 Finalization of instruments

As indicated already the stigma index questionnaire and tools developed by PLHIV for PLHIV (available at www.stigmaindex.org) was used to conduct the study. Issues that were considered in the study as per the standard stigma index questionnaires included background socio-demographic information of respondents, perceived causes of stigma and discrimination, access to work and services, internal stigma, rights, laws and policies, disclosure and confidentiality, access to health services, problems and challenges etc. In addition, since the Ghana study specified the inclusion of key populations in the study, a focus group discussion guide was developed to include specific questions to capture information about stigma and discrimination experienced by key populations. This was then finalized after discussions with NAP+, UNAIDS, GAC, the Local Coordinator and the International Consultant.

2.6 Selection of interviewers

The interviewers who are all persons living with HIV and are members of the National Association of Persons Living with HIV (NAP+) and the Network of Teachers and Educational Workers in HIV and AIDS, Ghana (NETEWAG) within the country were selected in collaboration with the President of NAP+, NETEWAG and the Ghana Education Service HIV Secretariat. The criteria for selection included persons who are openly living with HIV (i.e. they are comfortable disclosing their HIV-positive status to others), who have at least a tertiary level of education/preferably university or teacher training, have experience in conducting interviews for the collection of data and are available for the period of the study. The interviewers also needed to be literate with the ability to sufficiently read and write English in order to enable them accurately complete the questionnaires and adequately document the experiences described by the respondents.

Those who met the selection criteria were trained to collect both quantitative and qualitative data from their fellow colleagues also living with HIV as per the instructions of the Stigma Index Guide. The training was used as the final stage of screening of the interviewers and at the end of the process, 28 were selected from which 5 were tasked to be supervisors.



2.7 Training of interviewers and Supervisors

A four day training programme was conducted for 32 persons living with HIV and AIDS who had been selected from the first stage of the selection process. This was a comprehensive training using the People Living with HIV Stigma Index user guide, questionnaire and other research training materials. They were also trained in research ethics, confidentiality, interviewing, facilitating participatory group discussions and recording case studies. The Research team including the PLHIV reviewed and adapted to the Ghanaian context the standard data collection tools by interpreting key words into the key local languages spoken in the 10 regions. In addition, the interviewers and supervisors received guidance on dealing with difficult emotional situations and referring people for counseling or further sources of advice and information.

To enable interviewers appreciate the importance of the study as well as its intended empowering outcome for participants, the President of the National Association of Persons living with HIV (NAP+) was invited to perform the opening and welcome ceremonies for the training event. His presence throughout the training put the participants at ease and again emphasized to them the importance of the study. The President was involved in the study from planning to completion and will be also involved in the dissemination and use of the findings. The International Consultant who is an HIV Ambassador involved in the Anti-Stigma Campaign, provided input on HIV-related stigma and discrimination during the training.

The training was also the final stage for the selection of the interviewers and their supervisors. During the role plays to practice the conduct of interviews using the questionnaire, 28 out of the 32 were finally selected as interviewers (with 5 of them tasked as supervisors). The criteria used for the selection were ability to introduce the study to interviewees using the right words, display of good interviewing skills as well as ability to ask the questions in both English and the local languages. The selected interviewers were then given their interviewer codes starting from 01 to 28. The Local Coordinator (LC), who was given code number 29, also interviewed some PLHIV from the middle to upper-class, who are not likely to be members of NAP+.

2.8 The sample size

In order to have a sample that is large enough to capture the main features of the population as well as the variability from the main features, the team planned to have a large enough sample of 400 PLHIV proportionately distributed among the 10 regions according to the estimated population of PLHIV within each region (using the sample size calculation formula below*), however at the end of the field work 427 interviews had been completed (as in Table 1 below). This was to ensure that at least 40% of the respondents would be males. Although this does not reflect the direct male to female ratio of PLHIV in Ghana, the numbers were aimed at enabling the study team to adequately document the differences with respect to gender. The research team also collaborated with stakeholders and partners who work with key populations to ensure that as much as possible, this sample size included key populations such as commercial sex workers and men who have sex with men who are HIV positive.

***Sample size $S = n/[1+(n/P)]$**

$n = [(z\text{-score})^2 \times \text{Std Dev} \times (1 - \text{Std Dev})]/(\text{margin of error})^2$

Z-score for 95% confidence level = 1.96

Std Dev = 50% or 0.5

Margin of Error/Confidence interval = +/- 5% or 0.05

P = total population of PLHIV = 235, 982

$n = [(1.96)^2 \times 0.5 \times (1 - 0.5)]/(0.05)^2$

$n = (3.8416 \times 0.25)/0.0025$

$n = 385$

Sample size, $S = 385/[1 + (385/235, 982)]$,

$S = 384$ (rounded up to 400)



In addition to this sample size, Focus Group Discussions (FGDs) were conducted across the country in selected regions indicated in the session for sampling below describing the criteria for selection of the regions. A total of 6 FGDs were conducted (**with a total of 22 female and 12 male PLHIV discussants as well as 19 MSM PLHIV discussants**) as follows:

- » 1 PLHIV FDG with 5 females and 4 males and 1 MSM PLHIV FDG with 9 male participants in the Greater Accra Region
- » 1 MSM PLHIV FDG with 10 male participants in the Central Region
- » 1 PLHIV FDG in the Eastern Region with 6 females and 4 males
- » 1 PLHIV FDG in the Ashanti Region with three females and three males
- » 1 PLHIV FDG in the Northern Region with 8 females and one male

It is important to note that some of the experiences shared by some of the discussants of the FGDs and documented as case studies were not added to the report because they were experiences that had occurred more than 12 months before the study period (which is the period being taken into consideration for the study). However all those experiences have still been documented (attached as appendix) some with dates for reference purposes.

Three in-depth key informant interviews were also conducted with 2 MSMs and the Gender Focal Person of Maritime Life Foundation, an NGO that works to reduce HIV infection among KP in the Western Region.

2.9 Sampling strategy

Since the stigma index was designed to measure the extent to which PLHIV and key populations face stigma and discrimination, hence as much as possible, the calculated/estimated sample size had to be adhered to in order to maintain the statistical power of the study. The combination of purposive and random sampling method was used. This is because if only randomization was done to select the 400 respondents and some opted out of the study; there may be the possibility of the statistical power reducing (that is if the sample size became drastically reduced due to high drop-out rates). Respondents were therefore purposively selected in the step by step process (as described in the paragraph below) from treatment centres, support groups and drop-in centres for key populations, in order to capture the experiences of as many positive people with as diverse backgrounds as possible.

At the regional level, the ART centres, support groups and drop-in-centres were divided into urban and rural depending on where they are located. Two urban areas and two rural areas with populations that could be representative for the regions were selected from each of the regions, not too far from the location of the selected interviewers. Simple random sampling approach was then used from this stage. In each region, the Local Coordinator, supervisors and the interviewers (who are PLHIV) introduced themselves and the study to the medical professional in-charge of the selected ART sites using the introduction letter signed by the Director General of GAC.

The interviewers, some of whom were already “Models of Hope” in the selected ART sites were then given permission to speak to the clients of the centres who were willing to participate in the study. The interviewers took advantage of the clinic days (of the treatment centres) and meeting days of the support groups and drop-in centres to recruit willing respondents for the study. The Local Coordinator, (who is a PLHIV), with support from the Regional NAP+ Chairpersons assisted in the mobilization efforts for the study. PLHIV available and willing to participate in the study at the selected treatment centres, support groups and drop-in-centres in each region were interviewed till the required number of respondents for that region was attained. Where it was not possible for the interviewer to interview all the PLHIV present on the clinic day, arrangements were made to trace the remainder PLHIV to their places of residence or any convenient place agreeable to both parties. The interviewers were trained to ensure the selected respondents (study sample) were a mix of HIV positive people of different ages, sexuality and economic, social and educational backgrounds, a sample that would be representative of the epidemiological profile of HIV infection in the country.

For the purposes of the FDGs, the country was zoned into three geographical areas (coastal, middle and savannah). The coastal areas covering Greater Accra, Central, Western and Volta Regions, the middle zone covering Brong Ahafo, Ashanti and Eastern Regions and the savannah zone covering Upper East, Upper West and Northern Regions. The savanna belt featured the Northern Region because it is more central, has more defined urban and rural communities and has high population to represent the belt. In the Coastal belt, Greater Accra and the Western Regions were selected.

The Greater Accra Region was chosen because it is the capital city of the country and has a representation of PLHIV groups with varied background characteristics. Greater Accra region also has a considerably large numbers of key population



(such as men who have sex with men as well as commercial sex workers) PLHIV groups. The Western region where more identifiable groups are found was also selected in order to capture key populations. However because of the high levels of stigma in the Western Region, the PLHIV who are KP did not turn up for the FDG. The second FDG for the coastal zone was therefore conducted in the Central Region. In the middle belt the Ashanti and the Eastern Regions were selected; Ashanti Region being the most populous in the middle belt and Eastern Region having the highest HIV prevalence rate.

Table 1: Estimated Population of PLHIV in the Regions and the Estimated Sample Size

Region	Estimated PLHIV	Proportional Sample	Selected ART Sites	No. of interviewers
Greater Accra	34,631	71	Tema General Hospital, Dodowa Hospital, Ada Hospital, Ashiaman Polyclinic, Police Hospital, Ridge Hospital, 37 Military Hospital, Achimota Hospital, Amasaman Hospital and Pantang Hospital	4
Ashanti	44,132	74	Agogo Presby Hospital, Juaso Government Hospital, Konongo Government Hospital, Suntreso Government Hospital, KATH, Mampong Government Hospital, Bekwai Municipal Hospital, Jachie Pramso Hospital, Tafo Government Hospital, Kwadaso SDA Hospital, and Atonsu-Agogo Government Hospital	5
Eastern	22,883	40	Tetteh Quarshie, Mampong Hospital, Nsawam Government Hospital, St. Martins Hospital, Atua Government Hospital, Akuse Hospital, Koforidua Central Hospital and St. Joseph's Hospital	3
Western	20,705	36	Efia Nkwanta Regional, Takoradi and Kwesimintim Hospitals as well as Maritime Life (Drop in Centre)	2
Central	18,482	27	Winneba , Agona Swedru, Dunkwa Offin, Diaso, and Asafo Hospitals	2
Volta	18,686	35	Hohoe Municipal, Ho Regional, Aflao, Keta, Ho Municipal, Battor Catholic and Adidome District Hospitals.	3
Brong Ahafo	39,389	70	Sunyani, Techiman, Kintampo, Berekum, Dormaa, Atebubu, St. Mathais Catholic and Sene District Hospitals as well as Infanet Drop in Centre (Techiman)	4
Northern	22,134	38	Walewale District Hospital, Baptist Medical Centre, Tamale Teaching and Tamale Central Hospitals, West Gonja, Bole, and Yendi Hospitals and Sawla Polyclinic	3
Upper East	8,986	15	Bolga Regional Hospital, Navrongo War Memorial. Hospital and Bongo District Hospital	1
Upper West	5,954	10	Wa , Nadowli and Jirapa Hospitals	1
Additional Interviews by LC		10	In Ashanti and Greater Accra Regions	1
Total	235,982	427	78	28 + 1 LC

Prospective candidates for the FGD sessions were identified and recruited during the one-on-one interviews based on the following criteria:



- » *Interviewees/respondents who eagerly provided more information than solicited during the interview*
- » *Interviewees/respondents who showed the tendency of taking advantage of the opportunity presented by the study to express or pour out what has been “bottled up” in them.*
- » *Interviewees/respondents who appeared to be enjoying the interview and showed no sign of being in a hurry to end the interview.*
- » *Interviewers with one of the above criteria who were willing to participate in the FDGs*

The Regional NAP+ Chairpersons and the Local Coordinator assisted in mobilizing the participants for the FDGs once identified and the NAP+ regional offices were the venues for the FDGs.

2.10 Data Collection

The duration of data collection ranged between 10-15 days and data was collected from each of these 10 regions, proportionate to the estimated number of PLHIV within each region. A maximum of 2 interviews were conducted by each interviewer in a day. This was to ensure that enough time was spent to interview every respondent so they are allowed to fully express themselves during the time of interview. This was also to ensure that the interviewers did not get burn out from emotions they may have experienced as they listened to the respondents. The local and international consultants with support from the local coordinator, provided support to the interviewers and the supervisors throughout the period of the field work to deal with any emotions they experienced, as well as ensured the highest possible research and ethical standards were adhered to.

The field supervisors and consultants assisted the interviewers in documenting the case studies (which would be helpful in providing detailed illustrations of the problems and challenges encountered by persons living with HIV on a daily basis). Any interviewee/respondent with an experience or a case of interest and willing to share, was asked by the interviewer to return for a more in-depth qualitative interview on an agreed upon date and time. Cases of interest included peculiar instances or experiences by any respondent that have underlying demographic considerations (such as age, sex, marital status, socio-economic status), externalizing or internalizing blame, epidemiological trends, cultural and religious practices, rape or defilement, early marriage, legal issues etc. In addition the consultants moderated the focus group discussions (FDGs) with support from the field Supervisors and the Local Coordinator using FDGs discussion guide in 5 selected regions from the three zonal areas.

2.11 Translation of questionnaire

The questionnaire was not translated into the appropriate languages since printing the questionnaires in the various languages for all the 10 regions was going to be very challenging. Back to back translation and printing of the questionnaires in several languages was not going to be necessarily effective because most people in Ghana who are not able to read English, are also unable to read their own native language. Secondly, this process was not going to be cost effective as the questionnaires were administered verbally.

The selected Interviewers and Supervisors were multi-lingual (two or more predominantly spoken local languages for the regions from which they were selected) and they helped in the translation of the questionnaire which was subsequently pilot-tested at the training to ensure clarity and understanding by all. The questionnaires were therefore in English and verbal back translation of key words and phrases agreed upon during the training of the interviewers, were used.

2.12 Ethical considerations and confidentiality during data collection

A comprehensive procedure was followed to ensure that ethical issues were addressed and confidentiality was sufficiently maintained. Ethical approval was sought from the Ethical Review Committee of the Ghana Health Service (GHS), Health Research Division. In addition to this the consultants, interviewers, supervisors and data clerks signed the confidentiality agreement forms before participating in the study. All completed questionnaires and transcripts (from FGDS and case studies) were stored in a locked file with access limited to NAP+ officials and the Consultants. No respondents' name or address was recorded on the questionnaire nor on the informed consent forms; instead a unique identifying code which was used to identify respondents, was used to identify each individual's questionnaire. Each code included the country code of two digits; the network of persons living with HIV code of two digits; an interviewer code of two digits; an



interviewee/respondent's code of two digits; and the date on which the interview was conducted, of six digits (day/month/year).

Therefore the sample codes started with **GH/NP/...../...../...../** (GH = Ghana, NP = NAP+) the rest were then completed at the beginning of each interview after informed consent had been sought. The interviewers were also given their codes at the training. Informed consents of all respondents/interviewees were sought before the interviews commenced. Literate respondents were required to provide written consent, while illiterate respondents were required to provide oral consent after the purpose of the study had been clearly explained to them in a language they fully understood. Each respondent was also provided the option to refuse to participate or to withdraw from the interview whenever they desired as well as their freedom not to answer any question or to terminate the interview at any time. Participants were also informed that the questionnaire was anonymous and their answers were strictly confidential. The questionnaires were administered through a face-to-face means where the interviewer sat side by side with the interviewee/respondent to ask the questions. This was to provide the interviewees with a supportive environment during the interview process and encourage them to talk more openly about their experiences.

2.13 Quality control

Rigor, consistency and reliability were important concerns for the implementation of the persons living with HIV stigma index in Ghana, as they are for any research process. At the end of each week, the supervisors collected the completed questionnaires and went through to ensure the questions were answered in a logical manner. In cases where there was any reason for the supervisor, Local Coordinator and/or consultants (who were also on the field during data collection/field work), to suspect that a particular set of responses from a particular interviewer did not reflect the logical flow of responses, the supervisor or Local Coordinator (who are PLHIV) used the list of interviewees and questionnaire codes to cross check. This was to ensure that none of the interviewers manufactured falsified data. Each interview and research process also contained a referral and follow-up section and a quality control procedure panel. These were filled in by the interviewer after finishing the interview and, later, by the team leader back in the office. Each questionnaire included a quality check section on the last page which the team leader checked to ensure the interviewer had done a good job. As soon as the questionnaires came back to the office, they were checked by the team leader who subsequently queried any work that did not seem to be satisfactory.

2.14 Compensation

No monetary incentives were given for participating in this study, as indicated in the user guide, however refreshment was provided for participants of the focus group discussions. Also in order to ensure that interviewees/respondents did not incur any expenses in travelling, the interviewers tried as much as possible to conduct the interviews at locations within a walking distance from the interviewee/respondent. However in situations where this arrangement was not possible, the interviewees/respondents were reimbursed for the transport costs.

2.15 Data collation, entry, analysis and report writing.

As soon as the questionnaires were administered, the field supervisors undertook data quality checks while in the field and this involved checking the correct filling and signing of informed consent forms and checking, correcting and noting any discrepancies in the responses (missing data, responses not following the logic of the questions etc.). The questionnaires were then sent to a central data management centre at the office of the consultants, where a team of two dedicated data processing clerks entered the data into SPSS Software.

The quantitative data was then analyzed in close collaboration with NAP+, the TWG and GAC using SPSS (after the data entered into the database was cleaned) to generate simple frequency tables that were used to develop charts to graphically represent the information for easy interpretation and drafting of findings report. The units of analysis consisted of individual PLHIV and the indicators that formed both the basis for analysis and construction of the index included:

- » *Indicator #1: Background characteristics and household composition*
- » *Indicator #2: Experience of stigma and discrimination from other people.*



- » *Indicator #3: Access to work and health and education services.*
- » *Indicator #4: Internalized stigma.*
- » *Indicator #5: Rights, laws and policies.*
- » *Indicator #6: Effecting Change.*
- » *Indicator #7: Testing and diagnosis.*
- » *Indicator #8: Disclosure and confidentiality.*
- » *Indicator #9: Treatment.*
- » *Indicator #10: Having children*

Qualitative interviews (case studies and FGDs) were recorded, transcribed verbatim and emerging themes were used to support the findings of the quantitative analysis describing in detail the experiences of the PLHIV, their perceptions about stigma and discrimination and the changes that have occurred over the years due to efforts to reduce stigma etc. Most of the case studies were identified during the FGDs and these were also documented to provide sound evidence for policy and program interventions. An overall Stigma and Discrimination Index (S&DI) was calculated using 33 indicators grouped into 7 categories each of which included a composite of stigma indicators corresponding to the defined categories. The 7 broad categories were Exclusion, Access to work, health and education, feelings of the PLHIV respondents because of their HIV status, things the PLHIV are fearful of because of their status, knowledge of international and national laws and policies that protect their rights, reasons why the PLHIV did not try to get a legal redress for rights abused as well as issues around disclosure.



3.0 RESULTS

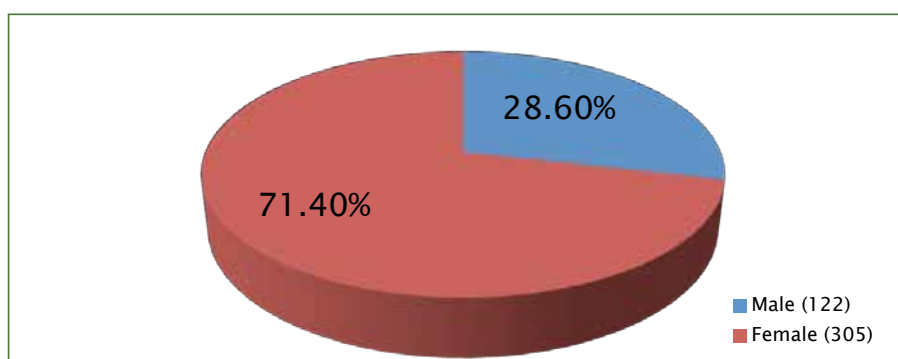
3.1 Background characteristics and household composition of respondents

This section presents the general background information about the study participants with a number of indicators on characteristics such as age, sex, location, marital status, educational background, employment status etc. to set the context and allow better understanding and interpretation of the results.

3.1.1. Sex of the respondents

Out of the total number of 427 PLHIV who participated in the study, 71.4% (305) were females with 28.6% (122) being males as shown in Fig. 1 below and this may be partly the reflection of the gender differential of HIV prevalence in the country. This was also reflected in the gender distribution of the participants for the general PLHIV FGD where 22 of the discussants were females and 12 were males. Except for the MSM PLHIV FGDs that had all 19 participants/discussants being males.

Figure 1: Sex of the respondents



3.1.2. Location of residence

Due to the sampling procedure it was agreed that the location of the participants would be classified into rural (combination of respondents indicating rural, small town and village) and urban (respondents indicating large town or city). In Ghana the classification of localities into 'urban' and rural are based on population size. Localities with 5,000 or more persons are classified as urban while localities with less than 5,000 persons are classified as rural¹⁵. The urban-rural divide for the participants of the study was almost 50/50 with 49.8% (n=211) of the participants from the rural areas and 50.2% (n=213) coming from the urban areas (Table 2). According to the 2010 population and housing Census 50.9% of Ghanaians are residing in urban communities while 49.1% are in the rural.

Out of the 122 male participants, 45.5% were from the rural and 54.5% were residing in the urban areas however more of the females (51.5%) were from the rural than those who resided in the urban areas (48.5%). It is obvious that residence in rural or urban area did not affect access to ART services since all the participants irrespective of their places of residence were recruited from the ART sites. Ghana has about 164 ART sites spread across the ten regions (Source NACP, 2013) increasing accessibility to treatment by PLHIV.

3.1.3. Age distribution of the respondents

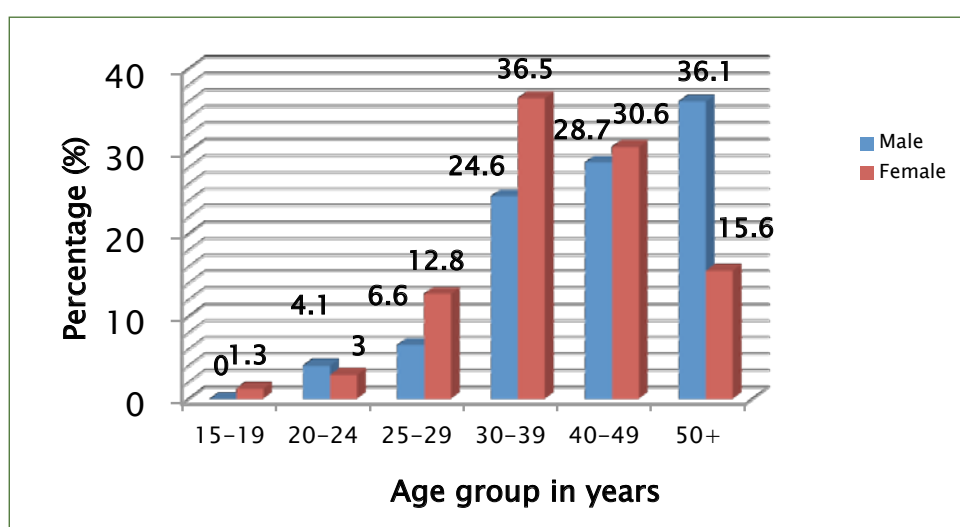
The age distribution of the participants by sex is also presented in Fig. 2. Most of the female participants (36.5%, n=111) were between 30-39 years whereas most of the male participants (36.1%, n=44) were 50 or more years. This same trend was also reflected in the focus group discussions for the general PLHIV groups where most of the participants/discussants were between 30 and 50+ years. However for the KP PLs FGDs (with MSM as participants), the participants were between the ages of 20 and 35 years.

¹⁵ 2010, Population and Housing Census Summary Report, May 2012, Ghana Statistical Services



In a nationally representative study implemented as part of a multi-country research on ageing to inform the draft national ageing policy and formal ratification of the policy, it was found out that the prevalence of HIV among adults aged 50+ was 2.3% (higher than among the general population) with the prevalence being high among women and urban dwellers¹⁶. It is therefore not surprising that the older age group of the respondents for this study (30-50+ years) were more than the younger age groups for both males and females. This also reflects the success of the ARVs with the older group of PLHIV living longer and healthier lives. The population of adults aged 60 years and above in Ghana has also been projected to double from 5.3% in 2014 to 10.5% in 2050¹⁷. Again older folks have a longer period of exposure to the risk of getting infected than the younger ones.

Figure 2: Age distribution of the respondents by sex



3.1.4. Duration living with HIV

The respondents were also asked about the duration they have been living with HIV and as indicated earlier these reported durations show the time since the respondents knew their status and do not show the exact time since infection. More than half of the respondents (51.7%, n=220) had lived with HIV for less than 5 years (Table 2). About 11% (n=47) reported to have lived for more than 10 years with HIV still reflecting the success of the ARVs, resulting in more people living longer, healthier and positive lives with HIV.

3.1.5. Current relationship status of the respondents

The current relationship status of the respondents is also presented in Table 2. Almost half of the males were either married/cohabiting and living with their spouses in the same household or working away with less proportion of the females (about 35%, n=109) being in such relationships. There was no difference between the number of males and females who were single, divorced/separated or widowed. Marital status of PLHIV is a very important indicator in the face of stigma and discrimination and the need for social and emotional support from someone very close. Generally, more than half of the respondents were either married/cohabiting or in one form of relationship or the other. Current relationship status was also analyzed by age of the respondents (Table 3) and out of the four respondents who were youth between 15-19 years, only one was married/cohabiting and sharing the same household with partner. Majority of married respondents were aged between 25 to 50+ years. Those who were widowed were also 25 years and above. The quantitative data supports results from the FGDs where higher incidence of female HIV-related widowhood were recorded (12.3% males and 17.4 % females).

¹⁶ Research Brief – Ageing and health in Ghana – findings from the Ghana Study on global AGEing and adult health (SAGE) Wave I

¹⁷ UN, 2013 as quoted in Research Brief – Ageing and health in Ghana – findings from the Ghana Study on global AGEing and adult health (SAGE) Wave I

**Table 2: Place of residence, duration with HIV and current relationship status of respondents by sex**

Respondents'	Male (%)	Female (%)	Total (%)
	122 (28.6)	305 (71.4)	427 (100.0)
Place of Residence/Location			
Rural	55 (45.5)	156 (51.5)	211 (49.8)
Urban	66 (54.5)	147 (48.5)	213 (50.2)
Duration with HIV			
Less than 1 year	19 (15.7)	53 (17.4)	72 (16.9)
1-4 years	43 (35.5)	105 (34.5)	148 (34.8)
5-9 years	46 (38.0)	112 (36.8)	158 (37.2)
10-14 years	9 (7.4)	29 (9.5)	38 (8.9)
15+ years	4 (3.3)	5 (1.6)	9 (2.1)
Current relationship status			
Married/cohabiting living with household	53 (43.4)	97 (31.8)	150 (35.1)
Married or cohabiting working away	6 (4.9)	12 (3.9)	18 (4.2)
In a relationship but not living together	13 (10.7)	46 (15.1)	59 (13.8)
Single	21 (17.2)	43 (14.1)	64 (15.0)
Divorced/separated	14 (11.5)	54 (17.7)	68 (15.9)
Widow/widower	5 (12.3)	53 (17.4)	68 (15.9)

Table 3: Current relationship analyzed by the age of the respondents

Current relationship status	Age of Respondents (yrs.)						Total
	15-19	20-24	25-29	30-39	40-49	50+	
Married or cohabiting and husband/wife/partner is currently living in household	1 (0.2%)	3 (0.7%)	15 (3.5%)	55 (12.9%)	47 (11.0%)	29 (6.8%)	150 (35.2%)
Married or cohabiting but husband/wife/partner is temporarily living or working away from the household	0	1 (0.2%)	1 (0.2%)	5 (1.2%)	3 (0.7%)	8 (1.9%)	18 (4.2%)
In a relationship but not living together	0	5 (1.2%)	12 (2.8%)	17 (4.0%)	18 (4.2%)	6 (1.4%)	58 (13.6%)
Single	3 (0.7%)	4 (0.9%)	12 (2.8%)	23 (5.4%)	11 (2.6%)	11 (2.6%)	64 (15.0%)
Divorced/Separated	0	1 (0.2%)	3 (0.7%)	26 (6.1%)	25 (5.9%)	13 (3.1%)	68 (16.0%)
Widower/Widow	0	0	4 (0.9%)	15 (3.5%)	24 (5.6%)	25 (5.9%)	68 (16.0%)
Total	4 (0.9%)	14 (3.3%)	47 (11.0%)	141 (33.1%)	128 (30.0%)	92 (21.6%)	426* (100.0%)

***One respondent did not provide an answer**

Of the respondents who were married, cohabiting or in some form of relationship (255), about a third (33.7%) had been involved with their partners between 1 and 4 years, 21.6% for between 5-9 years, and a third for more than 10 years. Only 34 of them had been together with their partners for less than a year.



3.1.6. Current sexual activity

About a fifth of the respondents (18.8%, n=80) said they were not sexually active whilst about a third of the 346 sexually active respondents were males. Out of the 122 male respondents, 86.1% (n=105) were sexually active and almost 80% of the female respondents also indicated current sexual activity. The most sexually active age group was the 30-39 years (Table 4) corresponding to the age distribution of the respondents in Fig. 1 above.

Table 4: Current sexual activity by age of the respondents

Are you sexually active at the moment	Age of Respondents (yrs.)						Total
	15-19	20-24	25-29	30-39	40-49	50+	
Yes	30 (0.7%)	11 (2.6%)	43 (10.1%)	122 (28.6%)	102 (23.9%)	65 (15.3%)	346 (81.2%)
No	1 (0.2%)	3 (0.7%)	4 (0.9%)	19 (4.5%)	26 (6.1%)	27 (6.3%)	80 (18.8%)
Total	4 (0.9%)	14 (3.3%)	47 (11.0%)	141 (33.1%)	128 (30%)	92 (21.6%)	426* (100.0%)

*One respondent did not provide answer

3.1.7. Respondents belonging to a specific group

Ghana is known to have a generalized epidemic with higher prevalence levels among groups who are considered high risk or key populations (KP). However, due to very high levels of stigma and its associated discrimination and because of social norms that designate such groups as social deviants coupled with other negative perceptions of the general population about belonging to such at-risk groups, not many of the respondents admitted belonging to these groups. For the purposes of this study these groups included men who have sex with men (MSM), gay/lesbian, sex workers, refugees, internally displaced persons (IDP), and members of indigenous groups, migrant workers and prisoners. There was no injection drug user among the respondents neither was there any of them who was transgender.

Table 5: Respondents belonging to specific groups by sex

Key Population	Male	Female	Total	
	N	N	N	%
MSM	13	-	13	26.0
Migrant Worker	-	6	6	12.0
Gay/Lesbian	6	4	10	20.0
Sex Worker	1	6	7	14.0
Indigenous Group	1	5	6	12.0
Internally displaced People	-	5	5	10.0
Refugee and asylum seekers	1	1	2	4.0
Prisoner	-	1	1	2.0
Total	22	28	50	100.0



Only 11.7% (n=50 out of 427) of the respondents indicated they belonged to one of the key population groups. The distribution of these groups by sex is presented in Table 5 above. Thirteen of them were MSM, 6 were migrant workers, 10 were gay/lesbians, 7 were sex workers and refugees were 2. In the two MSM PLHIV FGDs (held in the Central and Greater Accra Regions) however the research team managed to speak to 19 MSM who participated as discussants. This was made possible due to key informants and MSM peer educators who used the snow balling technique to invite the discussants. The FGD was held in a very secluded and discrete environment because of fear of being stigmatized and the possibility of someone finding out about the meetings and blowing the whistle for them to be exposed.

Out of the 49 members of key populations who provided answers for their location, 65.3% said they were located in urban areas and the rest from rural areas. None of them was below 20 years and about half of them were between the ages of 30-49 years (Table 6). Out of the 50 respondents who said they belonged to a key population, 42 (84.0%) said they were currently sexually active. When asked for how long they had been living with HIV, the majority (42.0%, n= 21) said they had been living with HIV between 1-4 years, 28.0% (n=14) said 0-1 year, 24.0% (n=12) said 5-9 years, 4.0% (n=2) said 10-14 years and only one of them had been living with HIV for 15 or more years.

Of the 46 members of key populations who shared information about their current relationship status, the majority 43.5% (n=20) said they were in relationships but not living together with the partners and only 13.0% (n=6) said they were married or cohabiting with the partners in the same household with the rest being divorced 17.4% (n=8) and widowed 8.7% (n=4).

Comments by an MSM PLHIV on the myth that MSMs brought “AIDS” (MSM PLHIV FGD, Accra)

“Do you know, there is this one information people carry around, they say MSMs brought HIV. That is the myth that they have about MSM that “you guys brought HIV”. So anytime an MSM dies they say that he is the cause of his own death. The first thing they see is when you are growing slim, you are not eating well and you are getting continuously sick, then they start tagging you with that. So when they tag you like that, what do you do? You do nothing, because it is not easy to be tagged with things like that. When we started working in the area of HIV, people who saw us said “the AIDS people are coming”. At that point it was a bit difficult for me, but I had to work on myself and I told myself that hey, even if I were positive, whose business was it. I am working to save lives and that is my focus; to save lives! People get Hypertension, Diabetes etc. and others work on them without complaining. People get Hepatitis B and its killing people more than HIV, others have Kidney failures and every three days they have to go and do dialysis and they are free to say that am going for dialysis, yet nobody says anything meanwhile his or her blood has gone bad and needs to be purified.”

Do you know one thing I am thinking of? It is all because, (excuse my word again) they are illiterates; they don't have information or they have not been educated about these kind of issues about HIV in particular. Because am a peer educator right and immediately you tell some people you are a peer educator they will tell you that you are one of them, you are positive and it raises this kind of stigma again. Then they will go ‘AIDS bii 3mba, HIV bii 3mba’ (the AIDS or HIV people are coming). The fact that they even say ‘AIDS bii’ (the AIDS people) indicates they don't have any knowledge about HIV”.

Table 6: Age distribution of respondents belonging to KP

Key Population	20-24		25-29		30-39		40-49		50+		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
MSM	3	50	5	38.5	5	23.8	-	-	-	-	13	26
Gay/Lesbian	2	33.3	4	30.8	4	19.0	-	-	-	-	10	20
Sex worker	-	-	3	23.1	4	19.0	-	-	-	-	7	14
Refugee/Asylum Seeker	-	-	-	-	-	-	-	-	2	40	2	4
Internally Displaced	-	-	-	-	3	14.3	1	20	1	20	5	10
Indigenous Group	-	-	-	-	2	9.5	3	60	1	20	6	12
Migrant	1	16.7	1	7.7	3	14.3	1	20			6	12
Prisoner	-	-	-	-	-	-	-	-	1	20	1	2
Total	6	100	13	100	21	100	5	100	5	100	50	100

**Table 7: Highest level of education attained by the respondents by sex**

Highest level of education attained by the respondents	Male (%)	Female (%)	Total (%)
No formal education	10 (8.2)	76 (24.9)	86 (20.1)
Primary school	44 (36.1)	156 (51.1)	200 (46.8)
Secondary school	44 (36.1)	62 (20.3)	106 (24.8)
Technical/college/university	24 (19.7)	11 (3.6)	35 (8.2)
Total			427 (100.0)

3.1.8. Highest level of education attained by the respondents

The highest level of education attained by each of the 427 respondents was also analyzed by sex and by the results presented in the Table 7, only a third of the respondents had had secondary school education or above and among these the proportion of males was more than females. Most of them (46.8%, n=200) had primary education with as many as a fifth not having any formal education. This conforms to the findings of the 2010 Population and Housing Census where 28.5% of the general adult population was found to be not literate. Thus being HIV positive does not seem to contribute to not having any formal education.

More of the respondents who had had at least secondary education (Table 8) were located in the urban areas than in the rural locations (81 compared to 58 respondents respectively) and more of the rural dwellers belonged to those who had not had any formal education than those from the urban locations (53 compared to 32 respondents respectively).

Ten (20%) of the key population respondents had had no formal education, 16 had primary, 17 and 5 said they had secondary and tertiary level education respectively. Thus most of the KP respondents were literate.

Table 8: Highest level of formal education attained by the respondents by location

Location of household	No formal education (%)	Primary (%)	Secondary (%)	Technical college /University (%)	Total (%)
Rural	53 (25.1)	100 (47.4)	47 (22.3)	11 (5.2)	211 (100.0)
Urban	32 (15.0)	100 (46.9)	57 (26.8)	24 (11.3)	213 (100.0)
Total	85 (20.0)	200 (47.2)	104 (24.5)	35 (8.3)	424 (100.0)

3.1.9. Employment status of the respondents

Employment status is one of the important indicators of one's access to financial resources and level of participation in economic activities. This is very important also because during the focused group discussions it came up strongly that higher levels of stigma and discrimination were experienced by less economically resourced PLHIV because they sometimes tended to be dependent on other relatives. From the results of the study (Table 9), majority of the respondents (163, 38.2%) said they were engaged in full time self-employment while as many as 89 (20.8%) said they were unemployed (not working at all). This also reflected in the FDGs where almost all the respondents indicated there were into petty trading.

It is worth noting that though there were more female respondents than males, more of the males were in full time employment as employees than the females. Only 14 out of the 122 males (15.7%) compared to 75 of the 305 female respondents (84.3%) were unemployed, thus more proportion of females were unemployed than the male respondents.

Table 9: Employment status of respondents by sex

Employment status*	Male (N)	Female (N)	Total (%)
Full-time employment (employee)	33 (56.9)	25 (43.1)	58 (13.6)
Part-time employment (employee)	8 (25.8)	23 (74.2)	31 (7.3)
Full-time employment (self-employed)	49 (30.1)	114 (69.9)	163 (38.2)
Doing casual work (self-employed)	16 (18.6)	70 (81.4)	86 (20.1)
Unemployed – not working at all	14 (15.7)	75 (84.3)	89 (20.8)

*multiple response



3.1.10. Presence of physical disability

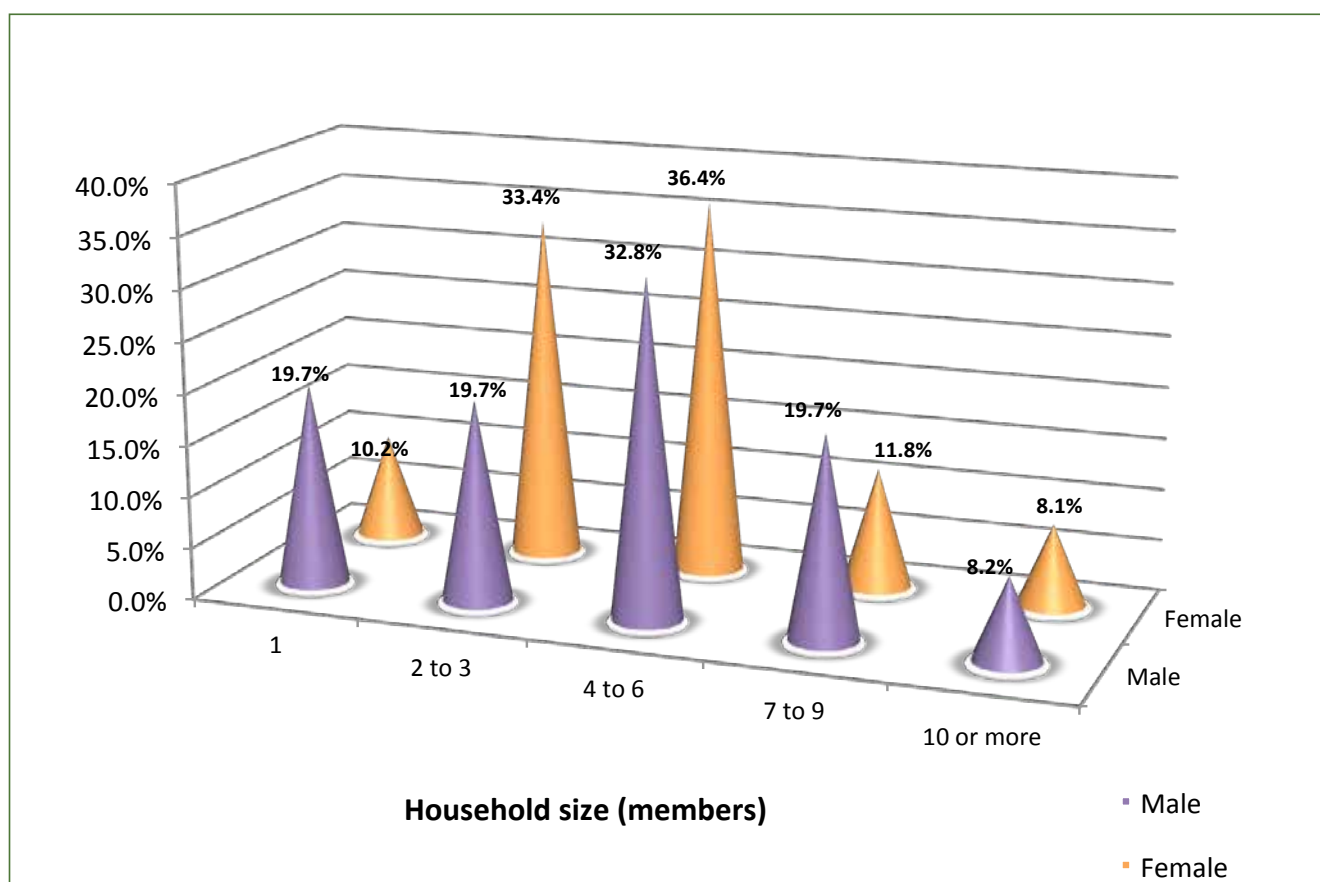
The presence of a physical disability and the possible ill health related to HIV infection may affect the quality of life of a person living with HIV by affecting his/her ability to engage in economic activity, thus decreasing his/her opportunities for generating income and access to basic needs and services. The presence of disability may also increase PLHIV vulnerability to stigma and discrimination. A total of 15 (3.5%) of the respondents (5 males and 10 females) had some form of physical disability including dislocation of the left or right hip, broken arm or limping due to vehicle accident, hearing impairment, stroke, part of one hand mauled by a machine or one leg paralyzed. It is worth noting that out of the respondents with physical disability, two thirds (10, 66.7%) were in full time self-employment working to earn an income to support themselves and their families.

3.1.11. Household size of the respondents

A household according to the 2010 Population and Housing Census is defined as a person or a group of persons, who lived together in the same house or compound and shared the same house-keeping arrangements. In general, a household consists of a man, his wife, children and some other relatives or a house help who may be living with them. However, it is important to note that members of a household are not necessarily related (by blood or marriage) because non-relatives (e.g. house helps) may form part of a household¹⁸ (Ghana 2010 Census).

The size of households with persons living with HIV is one of the very critical indicators of food security apart from income level of that household. The average/mean Ghanaian household size¹⁹ is 4 and in the study as many as 172 (56.4%) of the females and 74 (60.7%) of the males, had household sizes of 4 or more (Fig 3 and Table 10). There was no difference between the rural and urban location of residence within the various household size categories. However, more of the rural dwellers (128 out of 211) had large household sizes of 4 or above than the urban dwellers (115 out of 213).

Figure 3: Household size of the respondents by sex



¹⁸ 2010, Population and Housing Census Summary Report, May 2012, Ghana Statistical Services

¹⁹ Ghana Living Standards Survey Report of the Fifth Round (GLSS 5), Ghana Statistical Service, 2008

**Table 10: Household Size of respondents analyzed by sex and location**

Household Size	Male (%)	Female (%)	Rural (%)	Urban (%)
1	24 (19.7)	31 (10.2)	27 (12.8)	28 (13.1)
2 to 3	24 (19.7)	102 (33.4)	56 (26.5)	70 (32.9)
4 to 6	40 (32.8)	111 (36.4)	81 (38.4)	69 (32.4)
7 to 9	24 (19.7)	36 (11.8)	32 (15.2)	26 (12.2)
10 and above	10 (8.2)	25 (8.1)	15 (7.1)	20 (9.4)
Total	122 (100.0)	305 (100.0)	211 (100.0)	213 (100.0)

3.1.12. Orphans in the households of the respondents

The large numbers of orphans that were left by positive parents that died from AIDS is one of the devastating impacts of the AIDS menace in the society. For the purposes of this study, an orphan is described as one who lost one or both parents due to AIDS. As many as 38 AIDS orphans were living with the respondents with majority (60.5%) of them in urban locations (Table 11).

Table 11: Number of orphans in the respondents' households by location

Location	Households with 1 or 2 AIDS orphans (%)	Households with 3 or 4 AIDS orphans (%)	Households with 5 or more AIDS orphans (%)	Total (%)
Rural	11 (44.0)	4 (36.4)	0 (0.0)	15 (39.5)
Urban	14 (56.0)	7 (63.6)	2 (100.0)	23 (60.5)
Total	25 (100.0)	11 (100.0)	2 (100.0)	38 (100.0)

3.1.13. Household income of the respondents

The annual income level of the respondents was also calculated (using the estimates of their monthly household incomes) since this is an indicator of their socio-economic status, which has effect on their opportunities to access social and health services, as well as their vulnerability to stigma and discrimination. The median annual income was GHC3, 600.00, the minimum was GHC 24.00 and the maximum was GHC86, 400.00.

By the categorization of the annual income groups as shown in Table 12, about a third (33.1%, n=132) of the respondents belonged to the lowest annual income group and more of this lowest income group were from rural than urban locations. More of the male respondents belonged to the highest income group than the females, while more of the female respondents belonged to the lowest income group than the males. The daily income for the lowest income group was from 0 - GHC7.40, barely above the minimum wage/income of GHC5.24 in Ghana. Thus more than a third of the 399 respondents, who gave responses for their monthly household income, were barely earning the minimum daily wage.

Only 40 of the respondents who belonged to one of the key populations gave responses for their average monthly income and out of these 42.5%, (n=17) were of the highest income group, 40.0% (n= 16) were of the lowest group and 17.5% (n=7) were in the middle income group.

The annual household income of the respondents was also analyzed by the highest level of education they had attained to see whether there was any relation between the two. From the results (Table 13) among all the three income groups, the majority were those with primary level of education. Most of the respondents who belonged to the lowest income group had either not had any formal education or had had only primary level education (110 out of 132, 83.3%). Education level did not seem to have any relation with annual income levels of the PLHIV who participated in the study.

**Table 12: Household income by sex and location**

Annual Income Category	Income Value (GHC)	Male	Female	Total	Rural	Urban	Total
Lowest Income	0–2,700	26 (22.2%)	106 (37.2%)	132 (32.8%)	72 (36.7%)	60 (29.6%)	132 (33.1%)
Middle Income	2,700 – 5,400	32 (27.4%)	70 (24.6%)	102 (25.4%)	45 (23.0%)	57 (28.1%)	102 (25.4%)
Highest Income	5,400 and above	59 (50.4%)	109 (38.2%)	168 (41.8%)	79 (40.3%)	86 (42.4%)	165 (41.4%)
Total	-	117 (100%)	285 (100%)	402 (100%)	196 (100%)	203 (100%)	399 (100%)

Table 13: Household income by highest educational level attained

Level of Education	Lowest Income		Middle Income		Highest Income	
	No.	% (N=132)	No.	% (N=102)	No.	% (N=168)
No Formal Education	40	30.3	19	18.6	18	10.7
Primary School	70	53.0	46	45.1	74	44.0
Secondary School	18	13.6	30	29.4	52	31.0
Tech/University	4	3.0	7	6.9	24	14.3
Total	132	100.0	102	100	168	100

For purposes of comparing with other countries, it was recommended in the user guide that the annual household income of the respondents be calculated using the current US Dollar rate. However, it is important to note that this may introduce a lot of purchasing power disparities. This is because the amount of food and other items a Ghanaian can purchase with an equivalence of one dollar for example will vary from that of another country. The median annual income in US Dollars was USD 1420.68 (GHC 2.534= 1 USD), the minimum was USD 9.47 and the maximum was USD 34,096.29. The lowest annual income group was earning USD 1,065.51 while the middle income group earned USD 2,131.02. When these values were divided by the number of days in a year (365 days) the minimum daily income was USD 0.03, median daily income of the respondents was USD 3.89.

3.1.14. Food insecurity of the respondents

The Rome Declaration on World Food Security and the World Food Summit Plan of Action, convened by the United Nations Food and Agriculture Organization, resolved that “food security exists when all people, at all times, have physical and economic access to sufficient, safe and nutritious food to meet their dietary needs and food preferences for an active and healthy life.”²⁰ Food security for a household means access by all members at all times to enough food for an active, healthy life. Food security includes, at a minimum, the ready availability of nutritionally adequate and safe foods, and an assured ability to acquire acceptable foods in socially acceptable ways; that is, without resorting to emergency food supplies, scavenging, stealing, or other coping strategies (USDA)²¹. Knowing how food secure the households of the respondents were, is therefore very important since having enough food is crucial for the medication most PLHIV have to take every day.

²⁰ <http://www.globalharvestinitiative.org/index.php/what-is-food-security/>

²¹ <http://foodsecurityghana.wordpress.com/about-2/>

**Table 14: Food insecurity grouping by sex, location and key populations**

Food insecurity groups	Male	Female	Total	Rural	Urban	Total	KP
Not food insecure	103 (87.6%)	253 (84.3%)	356 (85.0%)	178 (86.0%)	175 (83.7%)	353 (84.9%)	35 (81.4%)
Moderately food insecure	2 (1.7%)	4 (1.3%)	6 (1.4%)	4 (1.9%)	2 (1.0%)	6 (1.4%)	2 (4.7%)
Severely food Insecure	14 (11.8%)	43 (14.3%)	57 (13.6%)	25 (12.1%)	32 (15.3%)	57 (13.7)	6 (14.0%)
Total	119 (100%)	300 (100%)	419 (100%)	207 (100%)	209 (100%)	416 (100%)	43 (100%)

As much as 85% (356 out of 419) of the respondents indicated there was never a day in the last month that they or any member of their households did not have enough food to eat (not food insecure group). Thus 15% said they were food insecure for some number of days in the last month. The respondents who said they were food insecure were without food for an average of 7.2 days, a minimum of 2 and maximum 31 days. The median days of food insecurity was 5 days.

Using the food insecurity groupings of 1-2 days without food for moderately food insecure and more than 3 days as severely food insecure, the food insecurity status of the respondents analyzed by sex is presented in Table 14. Only 13.6% (a little above one tenth) of the respondents reported to experience severe food insecurity in the last one month before the study. More females were severely food insecure than males.

There was no difference between those not food insecure in the rural and urban locations however more urban dwellers were severely food insecure than those from the rural locations. This is not surprising since food insecurity among the urban poor has become a very important issue in Ghana. Most people in urban areas, unlike their counterparts in rural communities buy their food. For residents of informal urban settlements, food insecurity is also the consequence of lack of space to store and cook food, lack of time to shop and prepare meals, inadequate access to clean water and often non-existing sewerage systems.

Out of the respondents who belonged to a key population, 14% (n=6) said they were severely food insecure in the last month.

3.2 Experiences of Stigma and Discrimination from other people

As described in the background, stigma and its associated discrimination may be experienced at different levels within different societal groups. Such forms of exclusion and abuses may include exclusion from social gatherings, religious activities, and family activities, being gossiped about, verbal insults, physical harassment and assaults. The PLHIV who participated in the study were asked how often they had experienced such exclusions and abuses from other people within the last 12 months so that the findings would reflect the current situation of stigma in Ghana.

3.2.1. Experiences of social exclusion by the respondents

It was found out from the results (Table 15) that as many as 161 of the 429 respondents (more than a third, 37.5%) had been aware of being gossiped about once, a few times or often. About a fifth of them (21.9%, n=94) had been verbally insulted or harassed; a tenth (10.3%, n=44) had been physically harassed or threatened; a little below a tenth of them (9.3%, n=40) had been excluded from social gatherings and family activities (9.3%, n=40) and (8.9%, n=38) of them said they had been physically assaulted. There was generally no difference between the experiences of the various categories of social exclusion with sex (Table 16). However more proportion of females were verbally insulted or harassed or physically assaulted than the male respondents (female were twice assaulted than males).



“We need to work on ourselves a lot so that we don’t walk around thinking that someone is gossiping or talking about us. The thing is people talk. But the fact that people talk doesn’t mean that you have to think that people are talking about you. I have never heard anyone say I am positive and I don’t know if someone has met with others somewhere and the person has told them that I am positive. Ever since I got to know my status, I have never even thought of someone telling anyone about my status before so am always free.

It is none of anyone’s business and no one has asked me, “Hey, this one said you have this” before. Yes, you should not always have it at the back of your mind that people are sitting there so they will be saying you are positive. The fact that I have met this guy here at this meeting doesn’t mean the next time I see him with another person then they will be talking about me. Everything that has happened in here is finished, I won’t think of that” (MSM PLHIV FGD, Accra).

“I used to cook for the whole household but now that I have been diagnosed of HIV, I cook for only my children. My people don’t inform me about gatherings that are going on and if I go to help, they ask me to stop. I have a farm and because I am a widow, I sometimes need people to help me work on the farm. When I ask some young men in the community to help me on my farm, they do not show up whiles they go to help others do the same activities.

I was physically assaulted to the extent of having a dislocation on my left hand. My late husband’s brother weeded off my crops that I have sown on a land of a community member who willingly gave me a land to farm on so that my children can get food to eat. He weeded the maize crop off because according to him, I will transfer my virus into the land. I feel suicidal but because of my children: now that their father is dead, nobody will be there to take care of them if I die”. (Case Study from one respondent in the Northern Region)

Exclusion from religious activities recorded the lowest numbers (2.8%, n=12). Though some of the participants of the focus group discussions indicated that, some of the religious leaders provided a lot of emotional and spiritual support to them when they disclosed their status; others shared very bitter experiences of religious exclusion.

“I was a women’s leader in a church. A nurse I used to attend church with said what is inside me will infect the rest of the church members. She told everybody and I was removed and replaced. Church leaders must be educated about stigma and discrimination because they contribute a great deal to the stigma that has been going on in the church” (Female participant/discussant in the Eastern Region FGD).

The low level of religious exclusion recorded in the results is as a result of lack of disclosure of PLHIV status within the religious cycles. This was confirmed from the results where only 6.6% of the respondents had disclosed to their religious leaders. The presence at all of exclusion from religious activities is indicative of the fact that there is still a lot of advocacy work to be done to educate religious leaders and their congregation that being HIV positive does not connote any negative moral behaviours. A male participant in the Eastern Region FGD said *“about a year ago, there was a talk about HIV in our church and it was said that those who are HIV positive must not mix with people who are not infected. Somebody (a church member) got up and debunked that idea and gave some education on the route of transmission of HIV”*. No one has the right to exclude anybody from any gathering or activity regardless of the person’s class, sex, age, colour or health status and this must be made clear to the religious leaders and the congregation.

The reported cases of the various forms of social exclusion were again analyzed by the location of the respondents and the results (Table 15) showed that generally more respondents from rural locations experienced social exclusion than those from urban locations (60% compared to 40%). However for religious activities, more of those from urban location were excluded than those from rural locations. There was no difference between rural and urban residence with respect to experience of exclusion from social gathering and physical harassment or threats.

**Table 15: Experience of social exclusion by location**

Categories of Exclusion	Rural		Urban		Total	
	No.	%	No.	%	No.	%
Social Gathering	20	8.7	20	10.1	40	9.3
Religious gathering	5	2.2	7	3.5	12	2.8
Family activities	24	10.4	16	8.0	40	9.3
Gossiped about	87	37.8	74	37.2	161	37.5
Verbally insulted, harassed/threatened	52	22.6	42	21.1	94	21.9
Physically harassed/threatened	22	9.6	22	11.1	44	10.3
Physically assaulted	20	8.7	18	9.0	38	8.9
Total	230	100	199	100	429	100

3.2.2. Relation between social exclusion, educational and household income levels

Anecdotes and reports from some current studies have indicated that PLHIV who are uneducated or poorer (with lower income levels) tend to experience higher levels of the different forms of stigma and discrimination associated with HIV and AIDS than those highly educated and in wealthy households. The experiences of the different forms of social exclusion were accordingly analyzed against the income groups and highest levels of education attained by the respondents. In agreement to portions of the findings from a study that examined the contributors of HIV-related stigma and discrimination in Ghana²², the results (Table 17) showed that respondents who had attained tertiary level of education reported the lowest cases of social exclusion (less than a 10th of the cases), whereas those with no formal education or primary school level reported as much as 66.3% (277 out of 418) of the reported cases of social exclusion. However from the results 144 cases of the different forms of social exclusion were reported by the respondents from lowest income group compared to 168 cases from the higher income groups. Thus the highest income groups reportedly experienced more levels of stigma and its associated different forms of social exclusion than the lowest and middle income groups.

3.2.3. Perceived reasons for the forms of social exclusion

In order to distinguish between stigma associated with HIV and stigma associated with other factors, those respondents who reported having experienced these specified types of social exclusion were also asked about their perceived reason for the being excluded and the results are presented in Table 18. As many as 367 (representing about 86%) of the reasons mentioned were either because of HIV status or both HIV status and another reason (280 and 87 respectively). Less than a tenth of them said there were other reasons (36, 8.4%) and the others (24, 5.6%) said they were not too sure why they were being excluded.

22 Tenkorang E. Y. and Owusu A. Y. 2013. Examining HIV-related stigma and discrimination in Ghana: what are the contributors, Sex Health, 2013, July ;10(3):253-62

**Table 16: Experiences of social exclusion by respondents analyzed by sex**

Frequency of exclusion	Social Gathering		Religious Activity		Family Activity		Gossiped about		Verbally insulted or harassed		Physically harassed/threatened		Physically Assaulted	
	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female
Total No. of Respondents	122 (100%)	305 (100%)	122 (100%)	305 (100%)	122 (100%)	305 (100%)	122 (100%)	305 (100%)	122 (100%)	305 (100%)	122 (100%)	305 (100%)	122 (100%)	305 (100%)
Never experienced	109 (89.3%)	277 (90.8%)	117 (95.9%)	298 (97.7%)	112 (91.8)	275 (90.2%)	78 (63.9%)	190 (62.3%)	100 (82.0%)	233 (76.4%)	113 (92.6%)	270 (88.5%)	115 (96.3%)	274 (89.8%)
Once	7 (5.7%)	8 (2.6%)	-	4 (1.3%)	3 (2.5%)	2 (0.7%)	9 (7.4%)	21 (6.9%)	7 (5.7%)	25 (8.25%)	7 (5.7%)	17 (5.6%)	5 (4.1%)	20 (6.6%)
A few times	5 (4.1%)	12 (3.9%)	2 (1.6%)	3 (1.0)	6 (4.9%)	12 (3.9%)	22 (18.0)	46 (15.1%)	11 (9.05)	24 (7.9%)	2 (1.6%)	10 (3.3%)	2 (1.65)	6 (2.0%)
Often	1 (0.8%)	8 (2.6%)	3 (2.5%)	-	1 (0.8%)	16 (5.2%)	13 (10.7)	48 (15.7%)	4 (3.35%)	23 (7.55)	-	8 (2.65%)	-	5 (1.6%)
Total who experienced by sex	13 (10.7%)	28 (9.2%)	5 (4.1%)	7 (2.3%)	10 (8.2%)	30 (9.8%)	44 (36.1%)	115 (37.7%)	22 (18%)	72 (23.6%)	9 (7.3%)	35 (11.5%)	7 (5.7%)	31 (10.2%)
Total experienced N=427	41 (9.6%) N=427		12 (2.8) N=427		40 (9.4%) N=427		159 (37.2%) N=427		92 (22%) N=427		44 (10.3%) N=427		38 (8.1%) N=427	


Table 17: Experience of Social Exclusion analyzed by household income and educational level

Categories of Exclusion	Lowest Income		Middle Income		Highest Income		Total		No Form Education		Primary Sch.		Sec Sch.		Tech/Univ.		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Total number of respondents	132	32.8	102	25.4	168	41.8	402	100	86	20.1	200	46.8	106	24.8	35	8.2	427	100
Social Gathering	14	9.7	9	10.3	12	7.1	35	8.8	9	8.9	13	7.4	16	15.5	3	7.9	41	9.8
Religious gathering	4	2.8	2	2.3	7	4.2	13	3.3	2	2.0	3	1.7	6	5.8	1	2.6	12	2.9
Family activities	14	9.7	5	5.7	16	9.5	35	8.8	10	9.9	16	9.1	10	9.7	4	10.5	40	9.6
Gossiped about	55	38.2	31	35.6	65	38.7	151	37.8	33	32.7	62	35.2	34	33.0	20	52.6	149	35.6
Verbally insulted, harassed/threatened	31	21.5	21	24.1	35	20.8	87	21.8	28	27.7	39	22.2	2.1	20.4	6	15.8	94	22.5
Physically harassed/threatened	15	10.4	8	9.2	19	11.3	42	10.5	8	7.9	24	13.6	10	9.7	2	5.3	44	10.5
Physically assaulted	11	7.6	11	12.6	14	8.3	36	9.0	11	10.9	19	10.8	6	5.8	2	5.3	38	9.1
Total	144	100.0	87	100.0	168	100.0	399	100.0	101	100.0	176	100.0	103	100.0	38	100	418	100.0

Table 18: Reasons for Social Exclusion

Reason	Social Gathering		Religious Activity		Family Activity		Gossiped about		Verbally insulted or harassed		Physically harassed/threatened		Physically Assaulted	
	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female
HIV Status	7 (53.8%)	18 (64.4%)	1 (20%)	5 (71.4%)	3 (30.0%)	22 (73.3%)	26 (59.1%)	89 (78.1%)	14 (63.6%)	50 (69.4%)	4 (44.4%)	24 (68.6%)	1 (14.3%)	16 (51.6%)
Another Reason	2 (15.4%)	2 (7.1%)	-	-	1 (10.0%)	1 (3.3%)	6 (13.6%)	4 (3.5%)	2 (9.1%)	3 (4.2%)	3 (33.3%)	5 (14.3%)	2 (28.6%)	5 (16.1%)
Both HIV another Reason	3 (23.15%)	5 (17.9%)	4 (80%)	2 (28.6%)	5 (50.0%)	4 (13.3%)	9 (20.4%)	14 (12.3%)	5 (22.7%)	16 (22.2%)	2 (22.2%)	5 (14.3%)	4 (57.1%)	9 (29.0%)
Not sure Why	1 (7.7%)	3 (10.7%)	-	-	1 (10.0%)	3 (10.0%)	3 (6.8%)	7 (6.1%)	1 (4.5%)	3 (4.2%)	-	1 (2.9%)	-	1 (3.2%)
Total	13 (100%)	28 (100%)	5 (100%)	7 (100%)	10 (100.0%)	30 (100.0%)	44 (100.0%)	114 (100.0%)	22 (100.0%)	72 (100.0%)	9 (100.0%)	35 (100.0%)	7 (100.0%)	31 (100.0%)



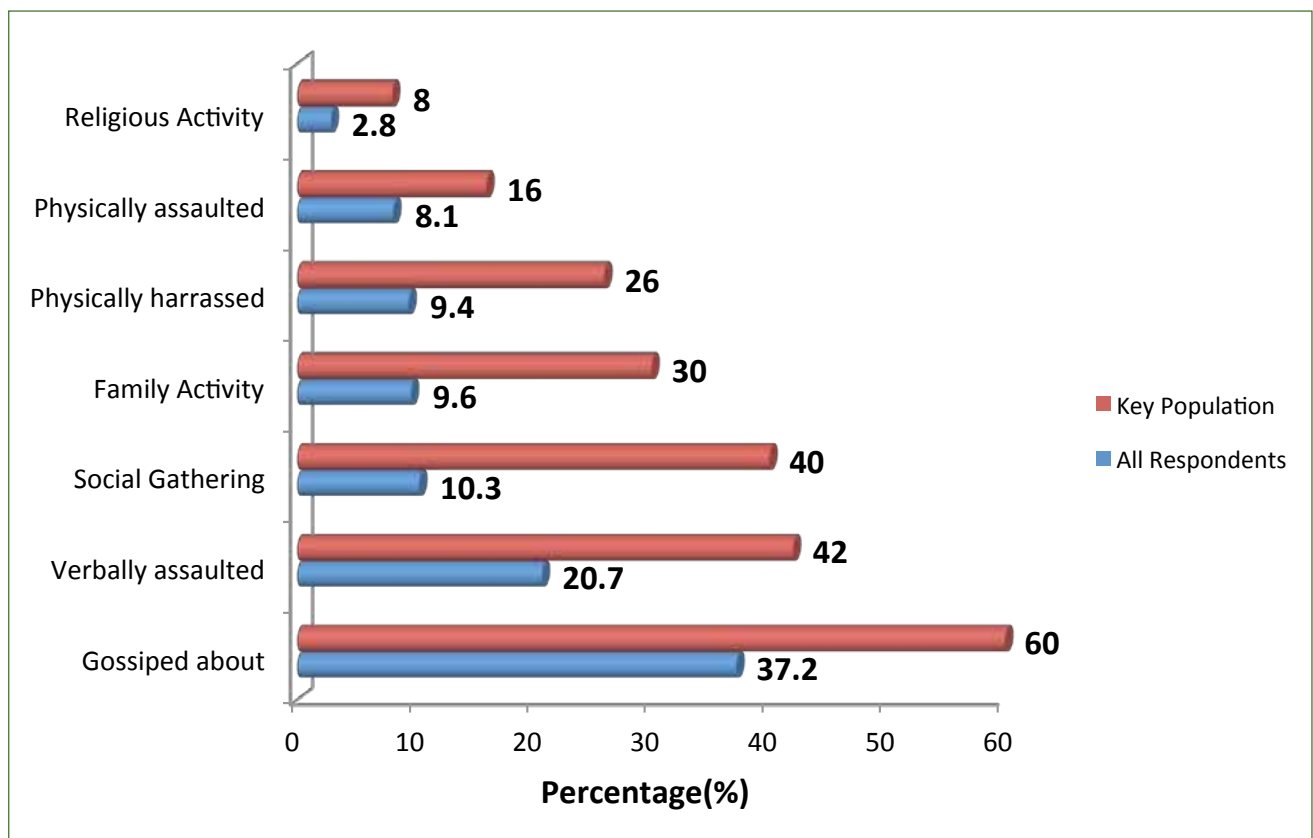
3.2.4. Experience of social exclusion among the key populations

The levels of social exclusion among respondents belonging to key populations were higher than among the general population of respondents (Figs. 4 and Table 19). There were as many as 111 reported cases of social exclusion (experienced once, a few times or often) among the key populations alone out of the total of 425 cases reported by the general population of respondents (i.e. 111 cases of exclusion experienced by 50 KP compared to 425 cases for 427 respondents).

Out of the 50 respondents that belonged to a key population, more than a half was gossiped about, 42% were verbally insulted, harassed or threatened. More than a third of them were excluded from social gatherings and a third excluded from family activities where as 26% were physically harassed or threatened. The least form of exclusion was from religious activities but it was almost three times the level among the general PLHIV respondents.

*“The stigma associated with MSM who are positive, is layered. Firstly, people think it’s because you are MSM that is why you are positive. Secondly people think MSMs brought the HIV disease and so God has paid them back in their own coin. And thirdly because we stigmatize against ourselves and we loose talk a lot. That is the problem. That is the main reason why most people didn’t want to join this Focus Group Discussion because they think one will get to know their status and go and tell someone else”.
(Quote from an MSM PLHIV participant of FGD in Accra)*

Figure 4: Experiences of social exclusion by all the respondents and key population



**Table 19: Experiences of Social Exclusion by Key Populations**

Categories of Exclusion	No.	% of total number of reported exclusion by the KP (N=111)	% of total KP (N=50)
Gossiped about	30	27.0	60.0%
Verbally insulted, harassed/threatened	21	18.9	42.0%
Social Gathering	20	18.0	40.0%
Family activities	15	13.5	30.0%
Physically harassed/threatened	13	11.7	26.0%
Physically assaulted	8	7.2	16.0%
Religious gathering	4	3.6	8.0%
Total cases of social exclusion	111	100%	

3.2.5. Perpetrators of physical assault

The respondents who reported having experienced physical assault in the last 12 months were asked who assaulted them. The perpetrators of physical assault against the respondents included husband or wife or partner, another member of the family, persons outside the household and unknown persons. The respondents' sex, location, age, highest educational level attained and household food insecurity group were analyzed against the perpetrators of physical assault and the results is presented in Table 20. More of the female respondents (31) experienced physical assault than their male counterparts (7) and the same trend was observed with each of the perpetrators. Thus more of the female respondents were physically assaulted by their husbands/partners, by other household members, by persons outside the household and by unknown persons.

More than half of the cases of physical assault (52.6%) were experienced by respondents from rural locations and the worst perpetrators in the rural locations were persons outside the respondents' households. Most of the respondents who experienced physical assault were between 30 and 49 years and the worst perpetrators were household members other than their spouses or partners. Thus apart from spouses or partners of PLHIV, the next very important groups that need to be targeted are the members of their households who need to be educated to understand why their support is very important for the much needed emotional care PLHIV need and hence they should not stigmatize or abuse them in any way.

More than half of the respondents who had experienced physical assault once, a few times or often had had only primary education and almost a third (29%) had not had any formal education. As many as 28 of them were not food insecure, but more of those severely food insecure experienced physical assault than the one respondent who was moderately food secure.

**Table 20: Perpetrators of physical assault by sex, age, location, education and food insecurity**

Variables	Husband/Wife/Partner		Another Household Member		Persons outside the Household		Unknown Person		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%
Sex of Respondents										
Male	1	14.3	-	-	5	71.4	1	14.3	7	18.4
Female	5	16.1	11	35.5	12	38.7	3	9.7	31	81.6
Location of Respondents										
Rural	4	20	5	25	10	50	1	5	20	52.6
Urban	2	11.1	6	33.3	7	38.9	3	16.7	18	47.4
Age of Respondents (years)										
15-19	-	-	-	-	1	100	-	-	1	2.6
20-24	-	-	1	100	-	-	-	-	1	2.6
25-29	1	14.3	2	28.6	3	42.9	1	14.3	7	18.4
30-39	3	23.1	5	38.5	4	30.8	1	7.7	13	34.2
40-49	2	16.7	2	16.7	6	50.0	2	16.7	12	31.6
50+	-	-	1	25.0	3	75.0	-	-	4	10.5
Educational Levels of the respondents										
No formal Edu.	1	9.1	5	45.5	5	45.5	-	-	11	28.9
Primary Sch.	4	21.1	4	21.1	8	42.1	3	15.8	19	50.0
Secondary Sch.	1	16.7	1	16.7	3	50	1	16.7	6	15.8
Tertiary/Uni.	-	-	1	50	1	50	-	-	2	5.3
Household Food insecurity Groups										
Not Food Insecure	4	14.3	6	21.4	14	50	4	14.3	29	76.3
Moderate	1	100	-	-	-	-	-	-	1	2.6
Severe	1	12.5	4	40	3	37.5	-	-	8	21.1

3.2.6. Experience of psychological pressure or manipulation by spouses or partners

As part of documenting the experiences of stigma and discrimination experienced by PLHIV, one key area which has to do with experiences of psychological pressure or manipulation by spouses or partners of the respondents was also studied. The frequency of experiencing such pressure and manipulation is tabulated by sex, educational level, years of living with HIV as well as food insecurity groups of the respondents (Table 21).

Out of the 425 respondents that provided responses for this question, 368 (86.6%) said they had never had such an experience and out of the 57 respondents (13.4%) who had had such an experience once, a few times or often, 37 were females with the rest being males. However the numbers who experienced psychological pressure and manipulation by their spouses or partners were analyzed within the sexes and it was found out that a higher proportion of the males 16.5% (20 out of 121 males) had such an experience than their female counterparts (12.1%, 37 out of 304 females). This is rather surprising since one would expect a higher proportion of the females to be experiencing such pressure and manipulation than the males.

A very classic example was given when one male focus group discussant for Ashanti Region shared his story.

“During the World AIDS Day (WAD) last year, my wife saw me with the T-shirt and stopped me from entering the house until I changed into another shirt. I had expressed interest in the Hearts to Hearts (H2H) Campaign but my wife told me that if I should appear on TV, by the time I got home, I would meet her dead. She stops me from having anything to do with HIV programmes because she does not want anyone to know her status from knowing mine. She has not disclosed to anyone. She even did not disclose her status to me until I found out myself and asked her to go with me to take the test together. I have been used as the example of a man who requested his wife to go with him for testing whereas she hid her status from him”.

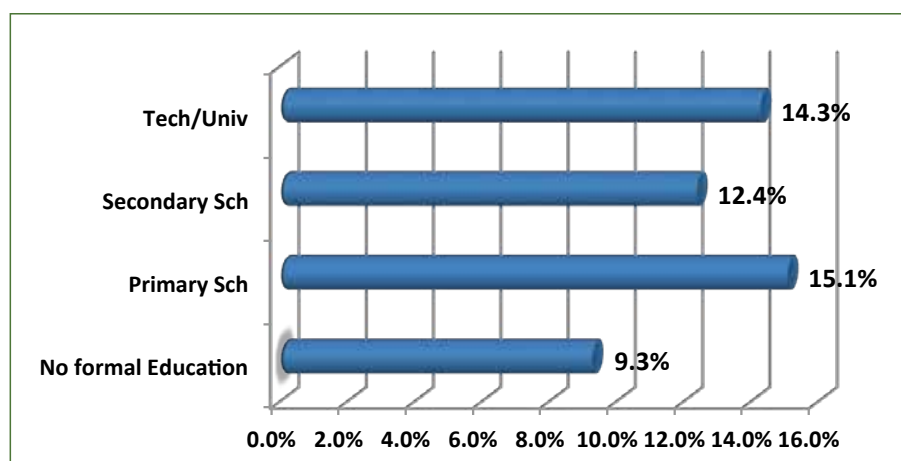


It is again surprising to note that respondents with no form of education were rather the least to have experienced psychological pressure or manipulation from spouse/partner at least once (Fig.5). Those with primary education were the most to experience psychological pressure or manipulation from spouse or partner with HIV positive status used, followed by those with tertiary level education and then those with secondary level. Since the questionnaire did not include the educational background of the spouses/respondents of the respondents it is difficult to tell whether the perpetrators of the psychological pressure were educated or not.

Table 21: HIV-related Psychological pressure by spouse/partner by sex, educational, duration of HIV & Food Insecurity Groups

Variables	Never		Experienced at least once		Once		Few Times		Often		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Sex of Respondents												
Male	101	83.5	20	16.5	8	6.6	9	7.4	3	2.5	121	100
Female	267	87.8	37	12.2	9	3.0	21	6.9	7	2.3	304	100
Total	368	86.6	57	13.4	17	4	30	7.1	10	2.4	425	100
Educational Level of Respondents												
No formal Education	78	90.7	8	9.3	1	1.2	6	7.0	1	1.2	86	100
Primary Sch.	169	84.9	30	15.1	7	3.5	17	8.5	6	3.0	199	100
Secondary Sch.	92	87.6	13	12.4	4	3.8	6	5.7	3	2.9	105	100
Tech/University	29	82.9	6	17.1	5	14.3	1	2.9	-	-	35	100
Duration of Living with HIV (years)												
0-1	66	91.7	6	8.3	2	2.8	4	5.6	-	-	72	100
1-4	126	85.1	16	10.8	7	4.7	11	7.4	4	2.7	148	100
5-9	133	85.3	23	14.7	4	2.6	15	9.6	4	2.6	156	100
10-14	34	89.5	4	10.5	3	7.9	-	-	1	2.6	38	100
15 and above	7	77.8	2	22.2	1	11.1	-	-	1	11.1	9	100
Food insecurity Groups												
Not food Insecure	312	88.1	42	11.9	14	4.0	23	6.5	5	1.4	354	100
Moderately Food Insecure	4	66.7	2	33.3	-	-	2	33.3	-	-	6	100
Severely Food Insecure	47	82.5	10	17.5	2	3.5	5	8.8	3	5.3	57	100

Figure 5: Experience of psychological pressure & manipulation from spouse/partner by educational level





There seemed to be an increase in the proportion of the respondents experiencing psychological pressure as the number of years living with HIV positive status increased (Table 22) however the experience level among those diagnosed 10-15 years ago was lower than those 15 years and above. This trend cannot be explained though one would expect that after living with HIV for a longer number of years, one's spouse would have gotten used to one's status and would have understood the need to rather provide psychosocial support and not exert pressure and manipulation. Unfortunately the questionnaire did not include a question to find out whether the spouse/partner was also HIV positive or not for the team to compare this indicator between those couples who were both positive and discordant couples. There still remains the fact that education must be increased so spouses or partners of PLHIV are encouraged to provide all the needed emotional and psychosocial support they need for them to live positive lives.

It is worthy to note that during the FGDs, it came up strongly that PLHIV are marrying other PLHIV and the reason they gave was that marrying their peers gives them the social and emotional support they need without fear of being stigmatized, discriminated or abused in any way.

Case of a woman who is afraid to accept marriage proposal for fear of stigma, FGD Ashanti Region

My husband and I tested negative before marriage. One year and three months later, after we had a baby, my husband fell ill, lost weight and started coughing. Our church minister advised that we go for a test and the result was positive. My husband was devastated, seemed to be going off his mind and did not sleep that whole night. I had to bring the minister and the Prayer Tower (prayer group) to pray for him. Since I had just had a baby, I looked fresh and healthy so he said it could not be possible that I would be positive. His relatives decided to take him to their hometown to seek treatment. Two weeks later, he died, - there was no medication then.

I was scared because of the pictures of HIV positive persons frequently shown on the television and prayed to God to kill me through an accident instead. I went for the test afterwards and I tested positive. A staff at the hospital consoled and counseled me very well. I shared my test result with our church Minister who prayed together with me. The Church supported me in prayer. I continued testing after the prayers and was still positive and so decided not to go for prayers anymore. Seven years later, I suffered a mild stroke. I had changed completely and my face became distorted. I was referred to a pastor and his wife who were both positive and they guided me to KATH. I had 2 children, but the first one died. I have not informed any member of my family. One member of my family (my sister) had once said that if any member of the family was positive, she would poison that person by putting rat poison into the person's food. I recently informed my daughter about my status. She did not speak for a week. She looked as if she had been taken ill. I counseled her and she has recovered.

Men are interested in me and what hurts so much and is my source of worry is that I cannot marry any of them because of my status. I would have to disclose my status, that person may not marry me but would end up disclosing my status to everyone resulting into so much stigma that I may not be able to deal with. If we are both positive then we would not stigmatize or discriminate against each other.

3.2.7. Perceived reasons for being stigmatized

The respondents were also asked why they thought they were being stigmatized and the responses are tabulated by sex and highest educational level of the respondents (Table 22) and presented in Fig. 6. The reason given by almost a quarter of respondents was people are afraid of being infected through casual contact with the respondents. A little above a fifth said people think having HIV is shameful and another fifth said they did not know or were not sure what the reason was. Surprisingly in a society of high religious beliefs and moral judgments this reason was the least mentioned by the respondents. It is possible that people's perception about being infected with HIV as a result of one's lowered morals is changing but there still remains a lot to be done to completely eliminate all forms of stigma and discrimination against PLHIV.

Almost all the respondents of the 6 FGDs indicated that there is still stigma against PLHIV but the level is not as high as before. They also indicated that though the level of stigma has decreased, persisting levels of stigma and discrimination in the Ghanaian society against persons living with HIV is as a result of the face given to HIV and AIDS several years ago at the early stages of the epidemic. They indicated that what drives stigma is the initial way the HIV epidemic was presented in the society - linking it to unacceptable behaviours. As illustrated in the vignette below:



“If someone is HIV positive, everyone regards them as being prostitute or promiscuous. The message about mode of transmission should change. One just needs one unprotected sexual contact to get infected whether a prostitute or not” (FGD, Ashanti Region).

“I think stigma and discrimination against PLHIV goes beyond illiteracy. I think it started with this communication about HIV being a chronic disease in songs and advertisement that were going on. Because it was painted as deadly, you need to be immoral to have HIV. That is the picture we got from the beginning. HIV is something from the immoral people, so if you get HIV it means you are a prostitute, you flirt, you just sleep around with people, you are MSM, you don’t have a vision. So that is the main reason for stigma now. Because even when you are amongst educated people, people who own organizations and they find out you are HIV positive, some of them refuse to accept you into their organization. And I know with the military, even now in the military, if you are HIV positive you won’t be accepted into the military and it is very bad. But they have to understand that people who have HIV live positively, some PLHIV even live healthier lifestyles than those who are negative do, so this shouldn’t be. I would say it all started with communication previously with the HIV pandemic or epidemic jingles, that is the main reason for the stigma people are facing now. Even now that kind of communication is still going on; when we keep saying that HIV prevalence is very high among MSMs then people will think that “yes, I said it, it’s the fault of these people, they brought this disease”. I am not saying they should not talk about the high prevalence among MSMs but they should couch the message in such a way not to spring up more levels of stigma and discrimination” (Comment from a discussant of MSM PLHIV FGD in Greater Accra Region).

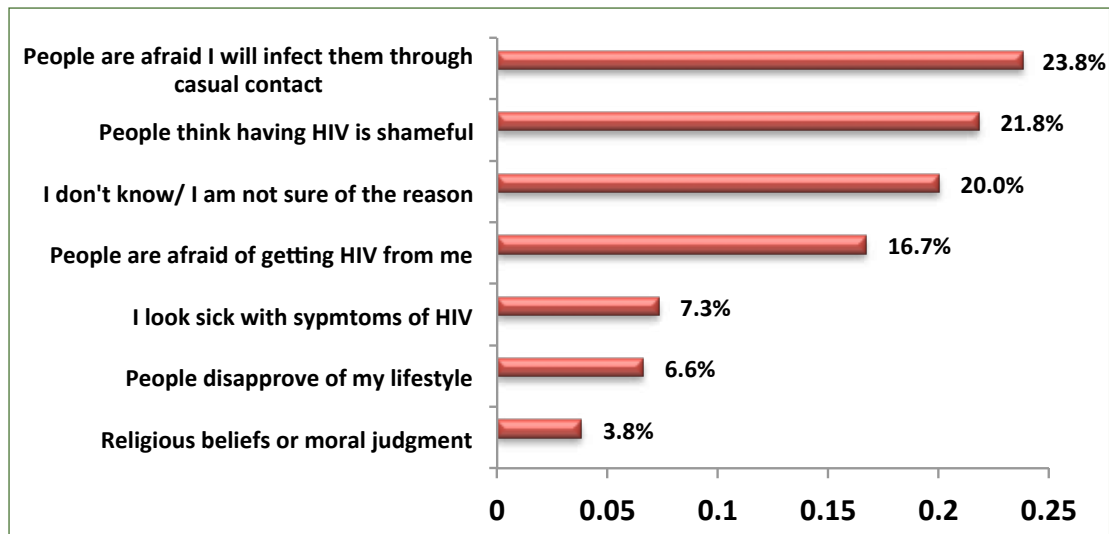
Another focus group discussant in the same FGD in Ashanti Region said

“the nurses and health care personnel should also give the information in public that the idea they had previously about the HIV pandemic was wrong, due to wrong information. Now, the good news if you test positive you would be put on treatment for you to live a normal, healthy and positive life etc. There is the TV programme where information about cancer is given, this same medium could also be used for the education on HIV so as to reduce stigma”.

Others were also of the view that the high levels of stigma and discrimination against PLHIV is due to lack of education on HIV issues.

“Stigma is high among those that don’t have much education about HIV and AIDS. A man refused to give me a handshake just because of my positive status” (FGD, Eastern Region).

The low level of knowledge about HIV among the adult Ghanaian populace was evident in the 2011 MICS²³ where it was reported that comprehensive knowledge about HIV prevention for women and men were 33.8% and 39.1% respectively.

**Figure 6: Why respondents think they were stigmatized****Table 22: Why respondents think they were stigmatized by sex and educational level**

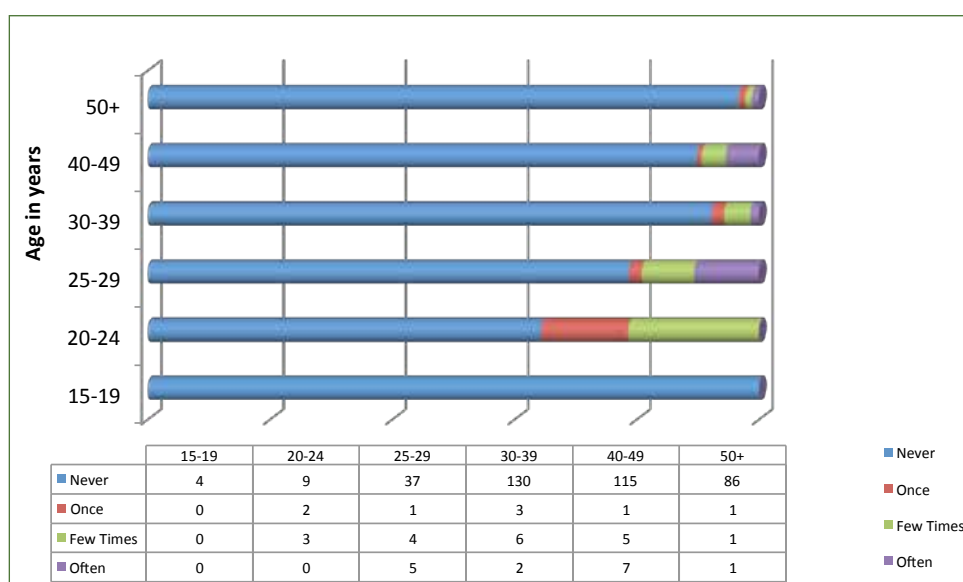
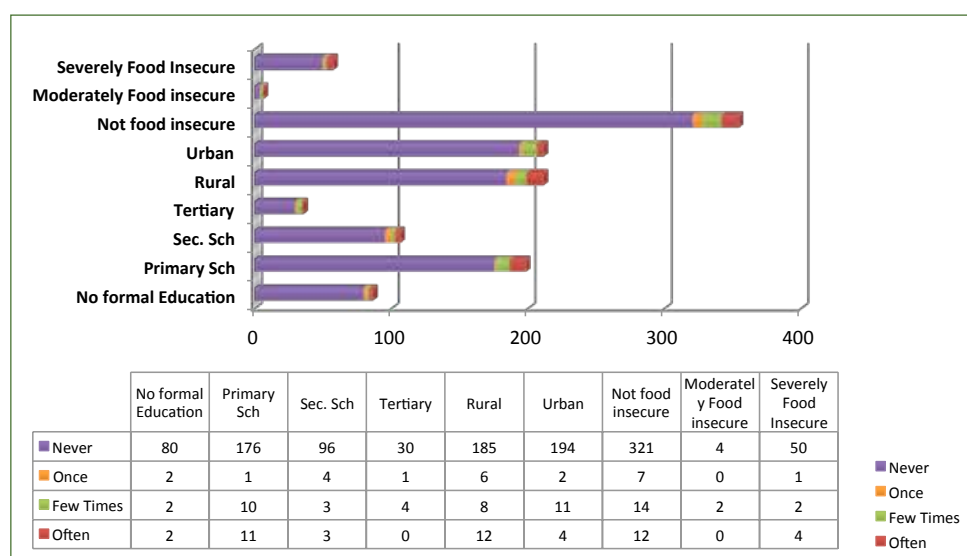
Why do you think you were stigmatized	Sex				Educational Levels								Total	
	Male		Female		No Formal education		Primary Sch		Secondary Sch		Tech/Univ.			
	No	%	No	%	No	%	No	%	No	%	No	%	No.	%
People are afraid of getting HIV from me	19	17.3	47	16.5	17	18.7	23	14.2	20	19.2	6	15.8	66	16.7
People are afraid I will infect them through casual contact	25	22.7	69	24.2	26	28.6	33	20.4	28	26.9	7	18.4	94	23.8
People think having HIV is shameful	26	23.6	60	21.1	23	25.3	31	19.1	23	22.1	9	23.7	86	21.8
Religious beliefs or moral judgment	4	3.6	11	3.9	3	3.3	6	3.7	5	4.8	1	2.6	15	3.8
People disapprove of my lifestyle or behaviour	11	10.0	15	5.3	7	7.7	9	5.6	5	4.8	5	13.2	26	6.6
I look sick with symptoms of HIV	6	5.5	23	8.1	6	6.6	15	9.3	7	6.7	1	2.6	29	7.3
I don't know/I am not sure of the reason	19	17.3	60	21.1	9	9.9	45	27.8	16	15.4	9	23.7	79	20
Total	110	100	285	100	91	100	162	100	104	100	38	100	395	100

3.2.8. Experience of sexual rejection

Sexual rejection is another form of enacted stigma against persons living with HIV especially among discordant couples for fear of the negative partner being infected. The respondents were accordingly asked to recount their experiences of sexual rejection in the last 12 months. From the results (Table 23) a total of 43 of the respondents had experienced sexual rejection at least once in the last 12 months with 17 being males and 26 females. This means 14.1% of the 121 male respondents (who answered this question) compared to 11.8% of the 304 females had experienced sexual rejection at least once in the last 12 months. For the female the highest frequency was often times and that for the males was a few times. When assessed by age (Fig. 7), it was found out that none of the respondents 15-19 years old experienced any sexual rejection in the last 12 months; 5 of the 20-24 year olds and 10 of the 25-29 year olds said they experienced sexual rejection at least once. More of the 40-49 year group (13) had experienced sexual rejection at least once in the last 12 months than the other year brackets.

**Table 23: Experiences of Sexual Rejection by sex and Duration of HIV**

Sexual Rejection	Sex		Duration living with HIV				
	Male	Female	0-1yr	1-4yrs	5-9yrs	10-14yrs	15+
Never (N=190)	104 (86.0%)	278 (91.4%)	64 (88.9%)	131 (88.5%)	142 (91%)	36 (94.7%)	7 (77.8%)
Once	3 (2.5%)	5 (1.6%)	-	4 (2.7%)	3 (1.9%)	-	1 (11.1%)
A Few times	10 (8.3%)	9 (3.0%)	3 (4.2%)	8 (5.4%)	7 (4.5%)	1 (2.6%)	-
Often	4 (3.3%)	12 (3.9%)	5 (6.9%)	5 (3.4%)	4 (2.6%)	1 (2.6%)	1 (11.1%)
Total	121 (100.0%)	304 (100.0%)	72 (100.0%)	148 (100.0%)	156 (100%)	38 (100.0%)	9 (100.0%)

Figure 7: Experience of sexual rejection by age**Figure 8: Experience of sexual rejection by educational level, location and food insecurity groups**



Again the respondents' experiences of sexual rejection were analysed by their highest level of education, location of residence and food insecurity groups (Fig. 8). Out of the 43 respondents that reportedly experienced sexual rejection, 6 were from the no formal education group, 22 from the primary school level group, ten from the secondary school level and 5 from the tertiary level group.

Twenty six of them were from rural residence and 17 from urban residence, thus 12.4% of the rural respondents that provided answers for this question had experienced sexual rejection at least once in the last 12 months as compared to 8.3% of their urban counterparts. More proportion of the rural residents experienced sexual rejection than their urban counterparts.

Thirty three of the respondents who had experienced sexual rejection at least once in the last 12 months were not food insecure, two were moderately food insecure and seven were severely food insecure. Food insecurity did not seem to have any relation with the respondents' experience of sexual rejection.

3.2.9. Experience of discrimination by other PLHIV

The respondents were also asked if they had experienced any form of discrimination from other persons living with HIV and the results are presented in Table 24. Thirty-two (7.5%) of the total number of respondents, indicated that they had experienced discrimination from other PLHIV at least once in the last 12 months. Fourteen were from rural residence and 17 from urban residence, thus more of those in urban residence have had such an experience in the last 12 months.

Table 24: Experience of Discrimination by other PLHIV by sex and location

Frequency of Discrimination	Sex		Location	
	Male (%)	Female (%)	Rural (%)	Urban (%)
Never	111 (91.0)	283 (93.1)	196 (93.3)	196 (92.0)
Once	4 (3.3)	5 (1.6)	3 (1.4)	5 (2.3)
A Few times	4 (3.3)	10 (3.3)	6 (2.9)	8 (3.8)
Often	3 (2.5)	6 (2.0)	5 (2.4)	4 (1.9)
Total	122 (100.0)	304 (100.0)	210 (100.0)	213 (100.0)

Those who reported having experienced discrimination by other PLHIV were analyzed by their membership of a PLHIV network or group and out of the 32 respondents who had experienced discrimination at least once from other PLHIV, almost 60% of them (19) said they belonged to a PLHIV network or group with the rest (13) not belonging to any PLHIV network (Fig. 9). It therefore appears that more of those who belonged to a PLHIV network/group experienced discrimination from other PLHIV than those who did not belong to any network or group. This is rather unfortunate since one would expect that being a member of a PLHIV network is to help one receive the psychosocial support needed to live a positively. This has to stop, it is absolutely not right for a person living with HIV to discriminate against another also living with HIV otherwise we would be fighting a lost battle against stigma and discrimination. However because there was no question to find out whether the perpetrators of the discrimination also belonged to a PLHIV network/group or not, it is difficult to infer or otherwise that members of PLHIV discriminate against each other.

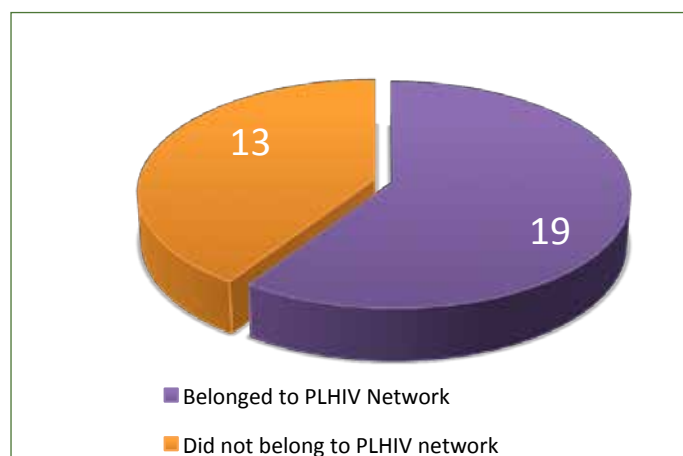
During the FGDs, it came up that PLHIV who were rich turned to discriminate against their peers who appear to be poor (by looking at their dressing and appearance) not wanting to even sit beside them at the ART clinic or at support group meetings. Stigma therefore exists among PLHIV, especially those of lower economic status who as a result are not able to afford healthy food. The wealthier ones would know immediately on seeing such persons and would move away if he/she sits by him/her. If they should have a cough, it is the last straw.

However concerning the cough a member in the FGD in the Ashanti Region advised the others not to take cough lightly. He said that could be TB and knowing that his immune response is not that good because of his positive status, he would get up quietly and move away if someone coughs without covering his/her mouth with a handkerchief so he does not compound his health situation with TB as an opportunistic infection. Another shared an experience of someone she had travelled with in a vehicle, who coughed all the time, stopped by a food vendor and kept on coughing without using a handkerchief. When she arrived at the hospital (at the chest clinic), she met that same person there and realized that he was aware he had TB but did not try to protect people around him from the cough so she rebuked him severely.



“There is always suspicion amongst the MSM group about HIV infection. If you gain a little weight others think you are on HIV medication; if you get involved with a known infected person there is suspicion that you are also infected and some even gossip about other people’s status even though they are also positive” (MSM PLHIV FGD, Central Region).

Figure 9: Experience of discrimination from other PLHIV by membership of PLHIV network/support group



Concerning stigma and discrimination from other PLHIV, all the MSM PLHIV who participated in the FGDs indicated that the level of stigma from other PLHIV is so high that they do not even want to be known as being positive and hence do not belong to PLHIV network/support groups. The few who belong to PLHIV network have also not disclosed their sexual orientation to their peers for fear of stigma and discrimination. One **MSM key informant from the Western Region** said

“MSM-PLs who are members of NAP+ have not disclosed that they are MSM to their fellow PLs, otherwise, they would be discriminated against. This is unfortunate because NAP+ is supposed to provide a great deal of support, especially emotional support for all PLHIV. The fact that there is discrimination against MSM-PLs by other PLs means future studies should include the latter to reach out to their peers. PLHIV support group is not fully benefiting MSM-PLs, due to the fear of being stigmatized”.

3.3. Access to work, health and education

Stigma and discrimination against PLHIV can result in them losing their places of residence, their sources of income and even prevent them from accessing health care services. This section therefore examines the extent to which the respondents were forced to change their places of residence, lost their jobs, refused employment, dismissed, suspended or prevented from attending an educational institution or denied health and sexual and reproductive health (SRH) services because of their HIV status. The timeframe for this assessment is still for the last 12 months in order to capture very recent incidences that give the true picture of what is currently happening.

3.3.1. Loss of accommodation or place of residence due to HIV status

A total of 51 of the 427 respondents (12%) indicated they had been forced to change their places of residence or been unable to rent accommodation at least once in the last 12 months and of this 16 were males and 35 were females. Thus 16 out of 122 males (13.1%) compared to 35 out of 305 females (11.5%) lost accommodation in the last 12 months, more of the males respondents therefore had such an experience than their female counterparts. More proportion of the respondents from urban residence reportedly lost their accommodation at least once within the period than those from rural residence (Fig. 10). More of those with primary level or no formal education had such an experience than those with secondary or tertiary level of education.

From all the six FGDs, there were a few of the participants who indicated that they were forced to leave their places of residence because of their HIV status either by their relatives or landlords/landladies. One respondent from the Eastern Region FGD said she stood her grounds and fought against the relatives because the house she was residing in was a family house. But others, who could not emotionally stand the pressure, had to leave because of fear of increasing levels of stigma and discrimination.



Figure 10: How often respondents had been forced to change place of residence by sex, location and educational level

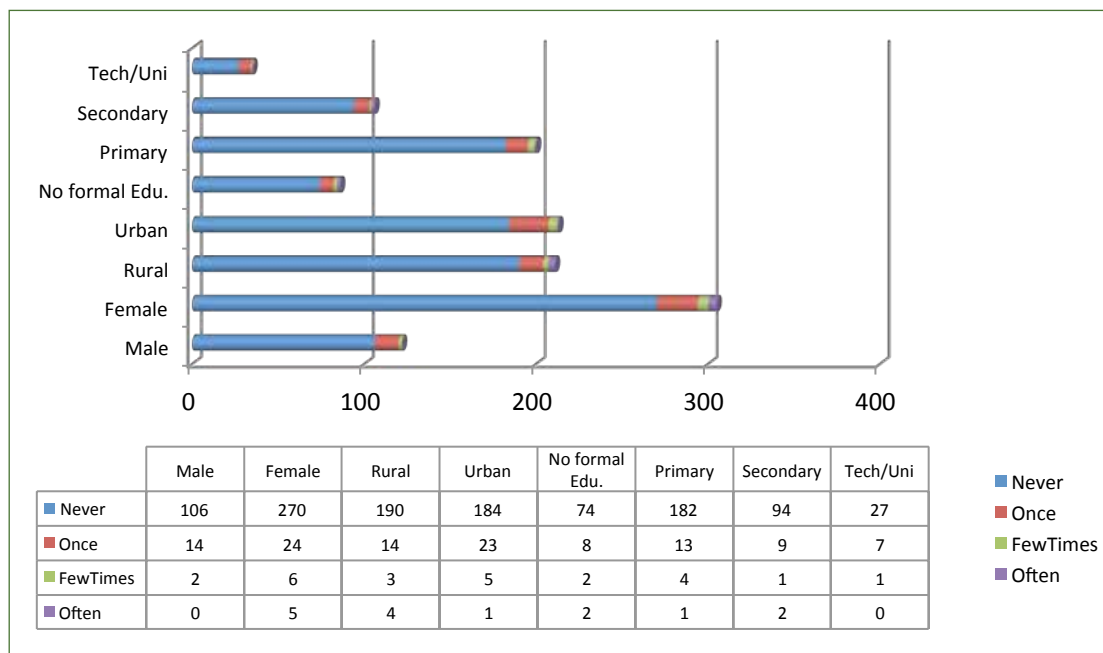


Table 25: Reason for loss of accommodation by sex, location, educational level and duration of HIV

Variables	Reason for losing accommodation				
	Because of your HIV status	For an(other) reason(s)	Both because of your HIV status and other reasons	Not sure why	Total
Sex					
Male	2(12.5%)	5(31.2%)	8(50.0%)	1(6.2%)	16(100.0%)
Female	20(57.1%)	6(17.1%)	8(22.9%)	1(2.9%)	35(100.0%)
Total N=51	22(43.1%)	11(21.6%)	16(31.4%)	2(3.9%)	51(100.0%)
Location					
Rural	10(45.5%)	6(54.5%)	6(37.5%)	-	22(100.0%)
Urban	12(54.5%)	5(45.5%)	10 (62.5%)	2 (6.9%)	29 (100.0%)
Highest Educational Level					
No Formal Education	8 (66.7%)	1 (8.3%)	3 (25.0%)	-	12 (100.0%)
Primary Sch	8 (42.1%)	5 (26.3%)	5 (26.3%)	1 (5.3%)	19 (100%)
Sec. School	4 (33.3%)	3 (25.0%)	5 (41.7%)	-	12 (100%)
Tech/Uni.	2 (25.0%)	2 (25.0%)	3 (37.5%)	1 (12.5%)	8 (100%)
Duration Living with HIV					
0-1 year (N=7)	2 (28.6%)	2 (28.6%)	2 (28.6%)	1 (14.3%)	7 (100.0%)
1-4 years (N=29)	9(31.0%)	7 (24.1%)	12 (41.4%)	1 (3.4%)	29 (100.0%)
5-9 years (N=11)	7 (63.6%)	2 (18.2%)	2 (18.2%)	0	11 (100.0%)
10-14 years (N= 3)	3 (100.0%)	-	-	-	3 (100.0%)
15+ years (n=1)	1 (100.0%)	-	-	-	1 (100.0%)

The respondents' perceived reasons for experiencing loss of accommodation in the last 12 months were also analyzed against their sex, location of residence, highest level of education and duration living with HIV (Table 25). For all the different attributes of the respondents the most stated reason for experiencing loss of accommodation was due to the



respondents' HIV status. More proportion of those who had lived with HIV for periods between 1-9 years suffered loss of accommodation than the others.

3.3.2. Loss of job due to HIV status

The respondents were also asked whether they had lost their jobs or sources of income in the last 12 months and as many as 69 (16.2%) of the 366 respondents indicated they had lost their jobs at least once. Though more female respondents (49) had experience loss of job at least once in the last months than males (20) the proportions within sex were not different, 19% of the total number of female respondents compared to 18.5% of the total number of male respondents (Table 26). The difference between rural and urban residence was also not much (37 compared to 31 rural and urban respectively). More of the respondents with no formal education or primary level education lost their jobs at least once in the last 12 months. More of the respondents in the highest income group reported losing their jobs or sources of income at least once in the last 12 months than those from the middle and lowest income groups (Fig. 11).

Table 26: Frequency of job loss in the last 12 months by sex, location and educational level

Variables	Never	Once	Few Times	Often
Sex				
Male (N=108)	88	10	6	4
Female (N=258)	209	27	15	7
Location				
Rural	137	19	11	7
Urban	158	17	10	4
Highest Educational Level				
No Formal Education	50	9	7	2
Primary Sch.	137	18	9	7
Secondary Sch.	80	8	2	2
Tertiary/Uni.	30	2	3	0
Status disclosure Co-workers and Employer				
Co-worker	22	5	1	-
Employer (Boss)	22	6	2	2
Age of Respondents				
15-19	2	-	-	-
20-24	10	2	-	-
25-29	25	11	-	2
30-34	102	13	7	1
40-49	90	8	11	2
50+	67	3	3	6
Key Populations				
MSM	8	1	1	-
Gay/Lesbians	8	1	-	-
Sex worker	5	2	-	-
Refugees	1	1	-	-
IDPs	4	1	-	-
Member of Indigenous Groups	5	-	-	-
Migrant workers	3	1	-	-
Prisoner	-	-	-	1



The reasons given by more than two thirds of the respondents (Fig. 12) for the loss of job were either because of HIV status or a combination of HIV status and other reasons. Only 7.1% said they were not sure of the reason for the loss of their jobs. This is very critical for policy because one's HIV positive status is not supposed to be used to fire him/her so far as Ghana's workplace policy is concerned. Formal and non-formal employers need to be educated on the workplace policy for them to comply and the policy needs to be implemented so PLHIV don't suffer such experiences of job loss.

“When I was diagnosed and thus got to know my status, I was very stigmatized against. I did not get it easy. I was a hairdresser and my mistress was trying to stop me from my work but I said no, I would continue to work. She even brought some elders to talk to me to stop but I refused. When I completed learning and I started to work on my own, the work I was doing (hairdressing) was seriously affected because my customers were told about my status by people who knew. I later stopped and went into trading. The room in my family house was being taken from me but I refused because it's a family house. But currently, I got married so am not in that house (female discussant of PLHIV FGD, Eastern Region)”

About 36% of those who lost their jobs either wholly or partly because of their HIV status said it was because they felt obliged to stop working due to poor health, 11% said it was because of discrimination by their employer or co-workers, 17% said it was because of a combination of discrimination and poor health while another 36% said it was because of another reason.

“My problem started long ago and it's still persisting. I was diagnosed and when I told my husband and asked him to assist me to get my drugs, he packed his bags and left town. In the past year, my problem is that my husband has gone in for another woman because of my status. He has asked me to leave the house and that he will not marry me again.”

I was told to take my son from the school he is attending because my son is also positive. I was selling 'gari and beans' at a Presbyterian Primary School in my town; somebody came to tell the school authorities that I am HIV positive. I was confronted and ever since whenever I went to the school to sell, nobody bought my food so I stopped. Now I am a petty trader” (Female participant PLHIV FGD, Eastern Region)

Figure 11: Experience of job loss by income, & food insecurity groups

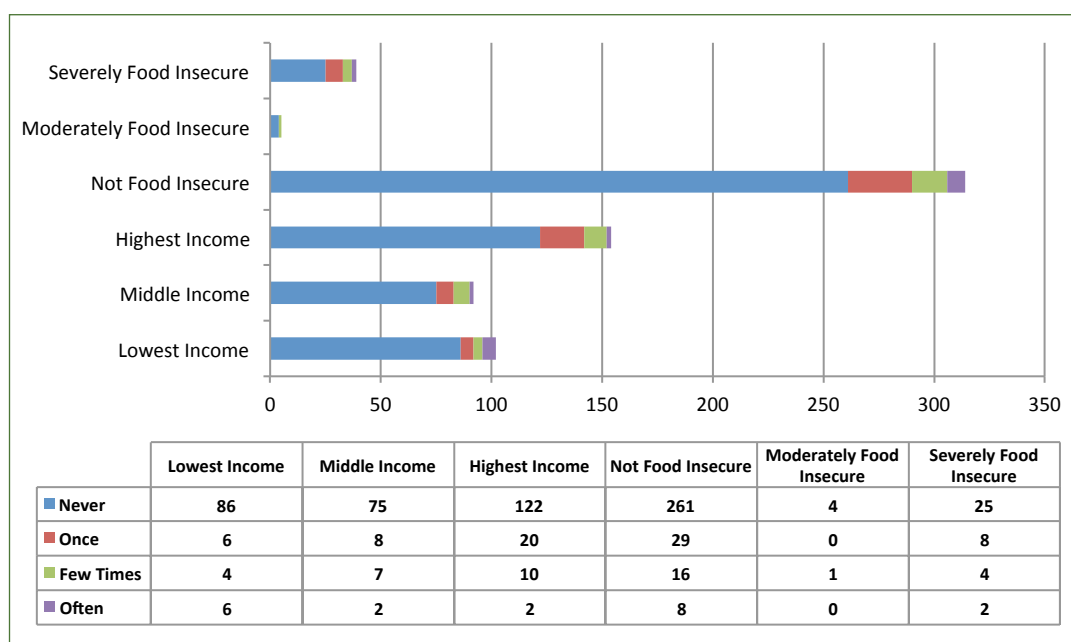
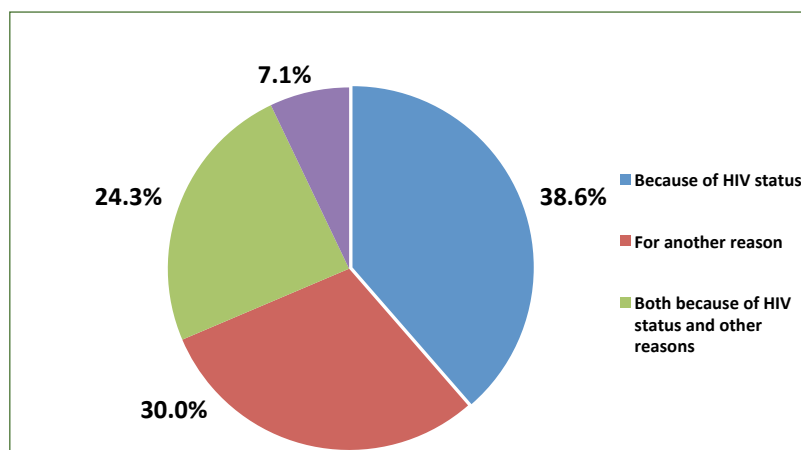




Figure 12: Reasons for losing job



Majority of the respondents from the FGD were self-employed (petty traders or artisans) and out of these some said they lost their sources of income because someone went to disclose their status and people stopped patronizing their trade. But those who had not disclosed or whose status had not been disclosed by someone else to their clients or people they work with said they have not lost their jobs because of their status.

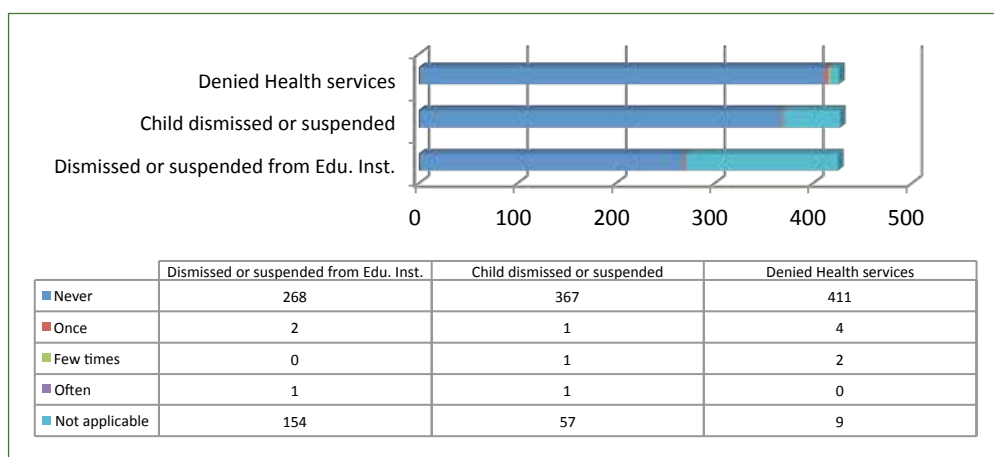
Some of the participants of the FGDs shared their experiences of job loss or loss of sources of income due to their status being disclosed. *“The Workplace policy may exist but it is not being upheld. One may not be forced to go for HIV test, but once your positive status is known, stigmatization is the order. I have been refused my due emolument after I voluntarily stopped working because it was discovered I was HIV positive (Male participant, PLHIV FGD in Ashanti Region).”*

3.3.3. Experiences of dismissal/suspension from education institution and denial of health services

The respondents were also asked to provide information on how often they, their child or children had been dismissed, suspended, or prevented from attending an educational institution as well as how often they had been denied health services including dental care because of their HIV status in the last 12 months and the responses are presented in Fig.13.

Three of the respondents indicated that they had been suspended or dismissed at least once from an educational institution because of their HIV status in the last 12 months; three said their child/children had had such an experience and six said they had been denied health services because of their HIV status within the same period. Thirteen and five of the respondents said they had been denied family planning and sexual and reproductive health services respectively in the last 12 months (Table 27). Though the questionnaire was in such a way that the interviewers could not probe further, this is completely unacceptable since everyone regardless of their gender, tribe, race or HIV status is entitled to access to education and health services. This is an infringement of the basic human rights of these respondents and hence policy makers need to ensure these rights are respected by all in the country.

Figure 13: Experiences of dismissal/suspension from education institution and denial of health services



**Table 27: Respondents who have been denied family planning or SRH services because of HIV**

Response	Denied family planning services		Denied Reproductive Health Services	
	No	%	No	%
Yes	13	3.1	5	1.2
No	297	69.9	420	98.8
Not applicable	115	27.1	-	-
Total	425	100.0	425	100.0

3.3.4 Institutional stigma of members of PL support group and/or network

Generally, work-related discrimination against members of PL support group or network was low apart from loss of time. This may be due to time needed to attend to one's health and general poor and/or deteriorating health. Only one in five respondents who were members of PL support group and network said they did not lose time and/or income in the last 12 months due to HIV status. About 23 percent and 20 percent said they had lost time or income once and a few times respectively in the past 12 months. About 37 percent often lose time and/or income due to HIV.

As shown in Table 28 an overwhelming majority of members of PL support group and/or network had never lost a job (85.9), refused employment or work opportunity (95.1) or have their job description changed or refused promotion (93.1) in the last 12 months. However, 7.1 percent had lost their job once while 5.1 percent had lost their jobs a few times in the last 12 months.

Table 28: PLHIV support group and/network members who reported various forms of discrimination

	Never		Once		A few times		Often		NA		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Lost a job (if employed) or another source of income	146	85.9	12	7.1	9	5.1	3	2	-	-	170	100
Loss of time/income	6	20.0	7	23.3	6	20	11	36.7	-	-	30	100
Refused employment/work opportunity	193	95.1	10	4.9	-	-	-	-	-	-	203	100
Job description changed/refused promotion	188	93.1	9	4.5	5	2.5	-	-	-	-	202	100
Dismissed, suspended or prevented from attending educational institution because of my HIV status	151	66.5	2	0.9	-	-	1	0.4	73	32.2	227	100
My child/children had been dismissed, suspended or prevented from attending an educational institution because of my HIV status suspended/prevented from attending institution	198	87.3	1	0.4	1	0.5	-	-	27	11.8	228	100
Denied health services including dental care	219	96.5	3	1.3	-	-	-	-	5	2.2	227	
Denied family planning services because of my HIV status	171	75.7	8	3.5	-	-	-	-	47	20.8	226	
Denied sexual and reproductive health services because of my HIV status	227	99.1	1	0.5	-	-	-	-	-	-	228	
Forced to change place of residence/ unable to rent accommodation	203	89	17	7.5	4	1.8	4	1.8	-	-	228	



Of the members of PL support group/network who attributed their loss of work or income to their HIV status (wholly or partially), 20 percent mentioned discrimination by their employer or co-worker as the reason, while 23.3 percent cited they felt obliged to stop working due to poor health. For another 20 percent, it was a combination of discrimination by employer/co-worker and poor health which accounted for the loss of work or income. About 37 percent had other reasons.

To assess discrimination and stigma in education against respondents who were members of PL support group/network, they were asked if they or their children were dismissed, suspended or prevented from attending an educational institution because of their HIV status. Regarding education, the stigma and discrimination was minimal. Less than one percent of the PL support group members had an experience of discrimination once in the last 12 months preceding the study. About 66.5 percent never experienced education-related discrimination in the last one year. For about 32.2 percent of the respondents in the PL support group, the questionnaire did not apply to them because they were probably not attending school the year preceding the study. Furthermore, less than 1 percent of the respondents in persons living with HIV support group experienced discrimination relating to their children's education in the last year preceding the study (see Table 28).

Similarly, PL support group members faced little discrimination as far as health services were concerned. Only 1.3 percent and 1 percent of the PL members were once denied health services including dental care and sexual reproductive health services respectively because of their HIV status in the last 12 months preceding the study. About 3.5 percent were once denied family planning services. Other discrimination experienced by persons living with HIV support group members is inability to rent accommodation or people being forced to change their accommodation because of their HIV status.

Below are some of the comments concerning institutional stigma that came up during the focus group discussions:

- » *Sometimes we are intentionally delayed or discriminated against. Nurses will stop to attend to others before they get back to us.*
- » *Attempts to preserve our confidentiality as PLHIV by isolating us and giving us preferential treatment at health facilities is making people ask a lot of questions to the health professionals who also turn to explain to them why we are given preferential treatment – thereby rather increasing stigma (the case of Agormanya in the Eastern Region). They should restructure the way PLs access drugs so that people will not notice. It will be better if all will access drugs, whether ART or any other drugs from the same place.*
- » *The distance from the OPD to the pharmacy is quite long and as you carry your folder through other sections to the pharmacy other patients stare at us. Our folders are different so it makes it obvious for other patients to identify us. One time I was going to get my folder and I heard another PL telling other nurses that ‘this is one of the guys’*
- » *As a peer educator I happen to work with other educators who are neither MSM nor PLs and when they got to know of some of us they started gossiping and shunning us.*
- » *There are times we go for meetings and persons who are not PLs join without us being pre-informed and we get exposed. When we object to that management will insist on it. The health workers who will attend a workshop with PLs must stop because after the workshop, some of them spread our status to others.*



Case study of a 34 year old female PLHIV in Kumasi, Ashanti Region

(She has serious self-stigma and covers her head with a veil whenever she has to go for her medication. She believes people only need one look at her face to know she was positive)

I am a 34 year old woman who got to know my status three years ago. Both mum and I were counselled before I was tested and my mum rejected the positive result outright and took me back home. I later went on my own to the Komfo Anokye Teaching Hospital (KATH), a different hospital, had my status confirmed and was put on medication. Due to the renovation at KATH, I was transferred to the SDA hospital but shortage of ARVs made me default. My health retrogressed often and did not regain my strength and health as when I was regularly complying with my medication.

I have helped my brothers complete their education, however, when I started falling ill often due to shortage of ARVs, these same brothers stopped our mum from providing me any assistance. They claimed she would in the end sell her clothes and even her head for my sake and it would all be in vain. My refusal to take herbal treatment has even compounded issues and made the whole family angry with me.

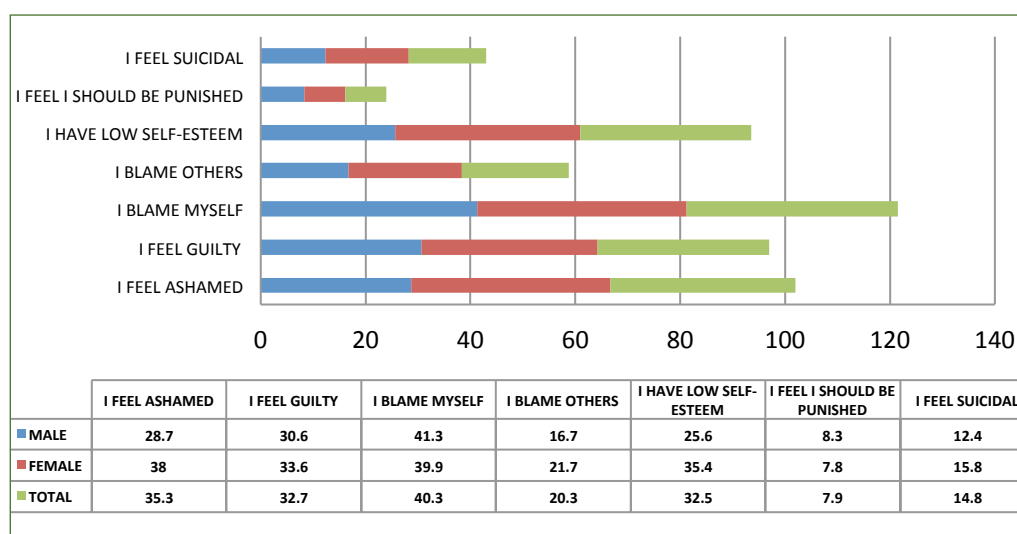
I had also been engaged to be married and got pregnant but delivered a still-born baby. My husband to be decided against marrying me because I was always sickly, and could not even do a simple thing of delivering a live baby and according to him; he had spent too much money on me, all for nothing.

I attempted suicide three times - I saw myself as useless, unloved, and unable to do a simple thing as keep a baby alive to term, always ill and at 34 years of age, life was not worth living. At the last attempt, I bought rat poison and went into the bush with my cup and water. I remembered I had not confessed the sin I was about to commit so I started doing so. Someone passing by heard my voice in the bush and came to find out who it was and what was going on. His sudden appearance frightened me, making me drop the cup of poison. He spoke to me and made me return home.

3.4. Internalized stigma –the way respondents feel about themselves and their fears

3.4.1. Indicators of Internal Stigma

Stigma, is not only how people perceive and behave towards another, but also relates to the internalized feeling that persons living with HIV have. Internal stigma is one of the most pervasive forms of stigma reported by PLHIV. Among the various indicators of internal stigma (Fig. 14), self-blame was the most common among both males (41.3%, n=50) and females (39.9%, n=119). A total proportion of 40.3% (n=169) of respondents said they blame themselves for their HIV infection. Similarly, 35.3% (n=149) said they feel ashamed, while 32.7% (n=137) said they feel guilty. Furthermore, 32.5% (n=136) reported having low self-esteem. Apart from these, more than one out of five women said they blame others for their condition. Various studies tend to show that in many of such cases, women blame their partners for being the source of their infection. Likewise 15.8% (n=47) of women said they feel suicidal, and the proportion of men in this category was 12.4%, (n=15)


Figure 14: Types of internal stigma felt by the respondents


PLHIV who belong to key populations seem to experience more internal stigma across all the indicators (Fig. 15) especially feeling ashamed, self-blame (50%), and feeling guilty or having low self-esteem (46%). Furthermore, 1 in 5 KP reported feeling suicidal. More proportion of the respondents from rural residents reported self-stigma than their urban counterparts. However more of the urban than rural respondents said they feel they should be punished.

Table 29: Internal Stigma by Age and Duration with HIV

Types of Internal Stigma	Age						
	15-19	20-24	25-29	30-39	40-49	50+	Total
I feel ashamed	3(75.0)	9(64.3)	19(41.3)	52(37.4)	43(33.9)	22(24.2)	148(35.2)
I feel guilty	1(25.0)	5(38.5)	16(34.8)	53(38.4)	35(27.8)	26(28.6)	136(32.5)
I blame myself	2(50.0)	6(46.2)	24(52.2)	59(42.4)	47(37.3)	31(34.4)	160(40.4)
I blame others	1(25.0)	2(15.4)	9(19.6)	38(27.50)	24(18.9)	11(12.2)	85(20.3)
I have low self esteem	1(25.0)	6(46.2)	17(37.0)	53(38.4)	36(29.0)	22(23.9)	135(32.4)
I feel I should be punished	-	2(15.4)	6(13.0)	11(8.0)	9(7.3)	5(5.6)	33(8.0)
I feel suicidal	1(25.0)	5(38.5)	9(19.6)	22(15.9)	18(14.3)	7(7.7)	62(14.8)
Duration with HIV (in years)							
	0-1	1-4	5-9	10-14	15+	-	Total
I feel ashamed	29(40.8)	62(42.2)	50(32.3)	6(15.8)	1(11.1)	-	148(35.2)
I feel guilty	28(39.4)	60(41.4)	45(29.2)	3(7.9)	-	-	136(32.6)
I blame myself	30(42.3)	69(47.6)	58(37.7)	10(26.3)	1(11.1)	-	168(40.3)
I blame others	14(16.5)	33(22.8)	32(20.6)	5(13.5)	1(11.1)	-	85(20.4)
I have low self esteem	28(39.4)	52(35.9)	43(27.9)	7(18.9)	5(55.6)	-	135(32.5)
I feel I should be punished	9(12.7)	14(9.8)	8(5.2)	2(5.3)	-	-	33(8.0)
I feel suicidal	14(19.7)	30(20.7)	11(7.1)	4(10.5)	3(33.3)	-	62(14.9)

Overall, internal stigma amongst PLHIV who are registered with support groups is also significant. However, compared to those who were not members of any support network the proportion is relatively lower. Figure 16 also presents the level of internal stigma among respondents who belonged to PLHIV network or support group compared to the level among all respondents. It shows that those belonging to a PLHIV group have lower internal stigma. PLHIV group members tend to blame themselves (34.8%, n=78), feel ashamed (30.3%, n=69), and have low self-esteem (26.5%, n=59). Despite belonging to a support group, more than one in ten (10.7%, n=24) of them still had suicidal tendencies.



Figure 15: Feelings of various forms of internal stigma by the respondents analyzed by sex and KP

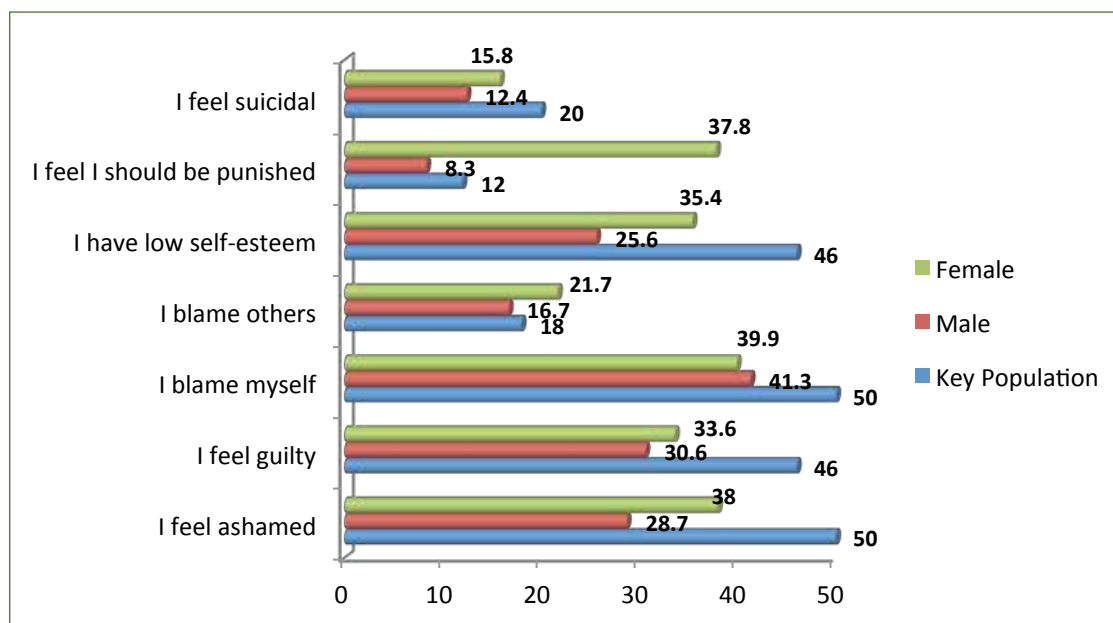
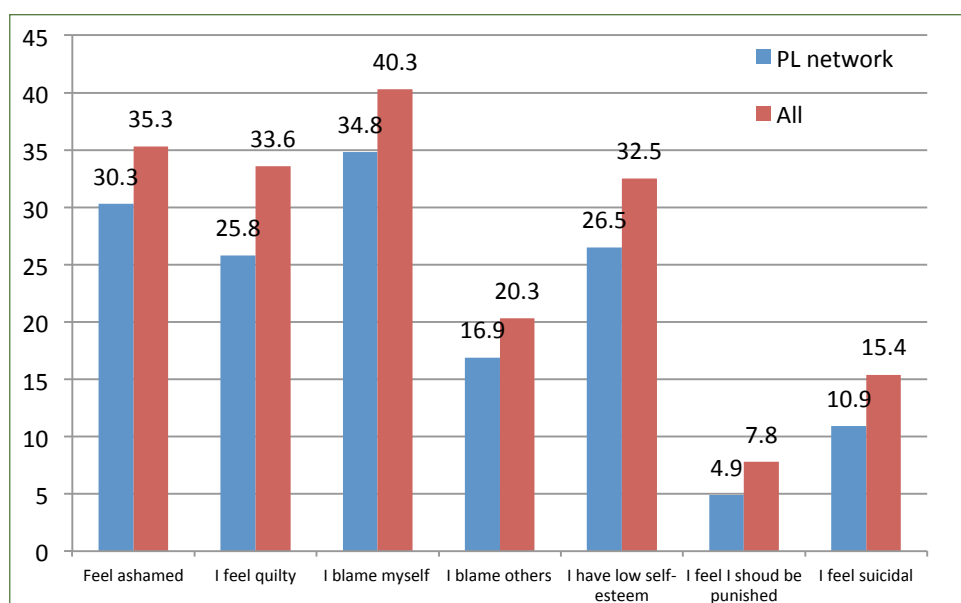


Table 30: Type of internal stigma by sex, location, membership of PLHIV network and KP

FEELINGS BECAUSE OF HIV	SEX		TOTAL	LOCATION		MEMBERSHIP OF NETWORK	KP
	MALE	FEMALE		RURAL	URBAN		
I feel ashamed	35(28.7)	114(38.0)	149(35.3)	83(39.7)	65(31.0)	69(30.0)	25(50.0)
I feel guilty	37(30.6)	100(33.6)	137(32.7)	69(33.2)	66(31.7)	58(25.8)	22(46.0)
I blame myself	50(41.3)	119(39.9)	169(40.3)	90(43.3)	78(37.5)	78(34.8)	25(50.0)
I blame others	20(16.7)	65(21.7)	85(20.3)	52(25)	33(15.9)	38(16.9)	9(18.0)
I have low self-esteem	31(25.6)	105(35.4)	136(32.5)	74(35.7)	61(29.3)	59(26.5)	21(46.0)
I feel i should be punished	10(8.3)	23(7.8)	33(7.9)	15(7.3)	18(8.7)	11(4.9)	6(12.0)
I feel suicidal	15(12.4)	47(15.8)	62(14.8)	37(17.8)	24(11.5)	24(10.7)	10(20.0)

Figure 16: Type of internal stigma by all respondents compared with those belonging to PLHIV network/support group





3.4.2. Effect of internal stigma on PLHIV behaviours

Apart from the negative feelings associated with their HIV positive status, respondents also reported changes in their behaviours especially with regards to the decision not to have more children (40.8%). The proportion of respondents in this category remained almost the same (the highest among all the behaviours) regardless of gender, location, and membership of a support network. This effect was still higher between the KP compared to the general population (Table 30).

Other significant behavioural changes included the decision not to get married (24.9%) and the decision not to have sex (22.4%). Significant variation was also observed among rural (28%) and urban (17.1%) respondents. This effect on behaviour (decision not to have sex) also constituted the third highest among respondents who belonged to a support network (Table 31). Apart from the decision not to have more children which ranked highest among KP followed by marriage avoidance, KP also tended to avoid social gatherings (34%) as well as interaction with family and friends (32%). Though on a relatively lower scale compared to other behavioural changes, 8.6% of respondents in general and 28% of KP avoided seeking medical attention. The high proportion of KP in this category is corroborated by the findings from the FGDs featuring MSMs who are HIV positive. This may be associated with the high incidence of institutional stigma and discrimination from some health providers reported by MSM key informants.

The very high level of self-stigma among the respondents was also reflected in the FGDs where majority of the respondents indicated they either blamed themselves, others or felt suicidal after knowing their status. Below are some of the statements from the participants of the FGDs on their self-stigma:

- » *“There are times that I think about the mistakes I did in the past and that alone brings depression and I look down on yourself. I wish I could turn back the hands of time.”*
- » *“There are times friends call you to join them chill out but knowing your status it makes you withdraw and feel lonely”*
- » *“There are times I wish I could disclose my status to other friends but I feel ashamed and afraid of not being accepted in their company.”*
- » *“I’m unable to mingle with my old friends. I feel ashamed so I’ve withdrawn from them.”*
- » *“I used to feel bad and ashamed but I’ve overcome that because this is not the end of life. I’m still living positively”*
- » *“I do feel ashamed and guilty because I think I’ve led a reckless life which has led to my present situation”*
- » *“People think we are cursed and this is the effect of being an MSM. This public perception makes me feel ashamed and don’t want to disclose my status, not even to my immediate relatives”*
- » *“Initially when I got to know my status and was told not to drink nor smoke in order to stay healthy, I felt I should rather die so I engaged more in drinking so I can die faster”*
- » *“The way people look at me judgmentally especially when I go for seminars/workshops, I feel ashamed about myself”*
- » *“There are certain routes in town that I fear or feel shy to use because people will stare at you so much that you feel they know about your condition”*
- » *“I have so many aspirations in life but sometimes I feel this cannot be and also fear that if my family gets to know of my status they will be disappointed in me”*

**Table 31: Effect of internal stigma on behaviour by sex, location, membership of PLHIV network & KP**

EFFECT OF INTERNAL STIGMA ON PLHIV BEHAVIOUR	SEX (%)		TOTAL	LOCATION (%)		NETWORK MEMBER	KP
	M	F		RURAL	URBAN		
Chosen not to attend social gatherings	12.5	11.3	11.6	13.5	10	8.9	34
I have isolated myself from family and friends	9.9	11.3	10.9	13.1	9	8.8	32
I took the decision to stop working	3.3	6	5.3	6.3	4.3	3.1	4
I decided not to apply for a job or promotion	5.1	5.3	5.2	3.6	6.9	5.5	16
I stopped or did not pursue education or training	5.1	3.6	4	3.7	4.4	5.1	8
I decided not to get married	23.1	25.7	24.9	28.6	21.6	24.2	46
I decided not to have sex	12.6	26.4	22.4	28	17.1	19	18
I decided not to have more children	39.2	41.4	40.8	42.6	39.5	43.9	50
I avoided going to local clinic	10.7	6.1	7.4	5.3	9.6	8.9	22
I avoided going to a hospital	2.5	0.7	1.2	1	1.4	0.9	6

Of the very few participants of all the FGD who said they had very little or no self-stigma one of them said:

“I am an ex-service man and a long distance driver. I knew that from my lifestyle and relationship with women and prostitutes, it was not surprising when I tested positive. I had 2 wives and a concubine. My wives are positive and my concubine is not so I decided to break off with her against her will. She still visits me but we do not have sex. She has tested three times and is negative. All my siblings and older children know my status. I was ill but did not get to the AIDS stage and thanks to the availability of the treatment I look very healthy so they do not believe that I am positive although I told them” (Male participant of PLHIV FGD, Ashanti Region).

Another participant in the PLHIV FGD in the Northern Region shared her experience of how she dealt with her self-stigma and even stigma from others. She said

“I used to feel like committing suicide because I felt the shame was going to be too much especially because of the gossips, but my mother encouraged me and I decided against the idea. There after I confronted anyone who stigmatized against me and asked if they knew their status and if they did not know their status I asked them to accompany me to the clinic so they can also get tested. From that time they stopped and I also have my peace of mind”.

3.4.3. Fear of stigma

PLHIV live in constant fear of being stigmatized and this as reported earlier is associated with the general lack of disclosure of their HIV status, particularly to individuals outside the health care delivery system. As demonstrated in Table 31, both males and females, regardless of location, fear being gossiped about the most. Indeed this fear is even higher when considered within membership of a support network (43.1%) and extremely high among KP (70%). A MSM PLHIV key informant in the Western Region stated that

“when MSM test positive, they fail to avail themselves for treatment not because the hospitals deny them but rather because of self-stigma which drives them further underground”.

In addition to the fear of being gossiped about 54% of KP are fearful of verbal insults, harassment or threats (Table 32). Similarly, a proportion exceeding half of KP and one-quarter of PLHIV in general, dread being denied sexual intimacy.

**Table 32: What respondents feared by their sex, location, membership of PLHIV network and KP**

THINGS FEARFUL OF	Sex		Total	Location		Membership of Network	KP
	M	F		RURAL	URBAN		
Gossip	38	38.9	38.6	42.8	36.6	43.1	70
Verbal insult/ harassment or threats	21.3	25.1	24	26.8	21.1	28.3	54
Physical harassment or threats	13.2	15.6	14.9	19	11.1	19.4	36
Physical assault	12.4	12.5	12.5	14.6	10.6	17.1	38
Afraid of being denied sexual intimacy	28.7	23.8	25.2	25.8	25	26.4	52

3.5. Rights, Laws and Policies

The realization of the rights of PLHIV entails commitment to ensure non-discriminatory access to relevant services within a supportive legal, economic and social environment²⁴. This entails putting in place a comprehensive legal and policy framework, plan of action with goals and a rigorous effort to implement and achieve the goals. Various international regional and national level instruments exist that urge governments to provide the enabling environment for the protection of the rights of PLHIV and ensure their access to basic services. These include the Declaration of Commitment on HIV and AIDS which seeks to protect the rights of people living with PLHIV and in Ghana the National Policy on HIV and STIs. Knowledge of PLHIV of the existence of these legislative instruments to protect their rights is very important to help assert their basic human rights including access to services for them to live positive lives.

This section examines the knowledge of the respondents about the existence of the Declaration of Commitment on HIV and AIDS at the global level and the National HIV and STI Policy which is at the national level. They were also asked about their experiences of abuse of their rights as persons living with HIV, whether they sought redress and the results of the process of the redress.

3.5.1. Knowledge about the Declaration of Commitment on HIV and AIDS

When asked whether they had heard of the Declaration of Commitment, 41.9% (179) of the respondents answered in the affirmative (Table 33) and out of this 59 were males while 120 were females. Thus 48.4% of the male respondents had heard of the Declaration compared to 39.3 % of their female counterparts. More proportion of the males said they had heard of the declaration than the female respondents.

Table 33: Heard of declaration of Commitment on HIV and AIDS by sex and age

Response	Sex		Total	How old are you (years)						Total
	Male	Female		15-19	20-24	25-29	30-39	40-49	50+	
Yes	59 (48.4%)	120 (39.3%)	179 (41.9%)	1 (25.0%)	3 (21.4%)	17 (36.2%)	57 (40.4%)	50 (39.1%)	50 (54.3%)	178 (41.8%)
No	63 (51.6%)	185 (60.7%)	248 (58.1%)	3 (75.0%)	11 (78.6%)	30 (63.8%)	84 (59.6%)	78 (60.9%)	42 (45.7%)	248 (58.2%)
Total	122	305	427	4	14	47	141	128	92	426

3.5.2. Knowledge about the National HIV and AIDS Policy

The respondents were also asked whether they had heard of the National Policy on HIV and STIs and out of the 417 who provided answers about a third (135, 32.4%) said yes, 44 were males and 91 were females. Within the sex groups more proportion of the males 36.7% (44 out of 120 male respondents) said they had heard of the national policy than the proportion of their female counterparts (30.6%). Those who said they had heard of the policy were asked whether they had ever had the opportunity of reading or discussing the contents and about 41% of them answered in the affirmative.



Again a higher proportion of the male respondents (48.9%) who had heard of the policy had read the policy than the proportion of female respondents (37%).

Table 34: Have you ever Heard or discussed content of the National HIV and STI Policy?

Response	Location		Highest level of formal education completed				Total
	Rural	Urban	No formal education	Primary school	Secondary school	Techn./Univ.	
Yes	23 (30.3%)	37(51.4%)	5 (23.8%)	22 (33.3%)	25 (53.2%)	8 (57.1%)	60 (40.5%)
No	53(69.7%)	35(48.6%)	16 (76.2%)	44 (66.7%)	22 (46.8%)	6 (42.9%)	88 (59.5%)
Total	76 (100.0%)	72 (100.0%)	21 (100.0%)	66 (100.0%)	47 (100.0%)	14(100.0%)	148 (100.0%)

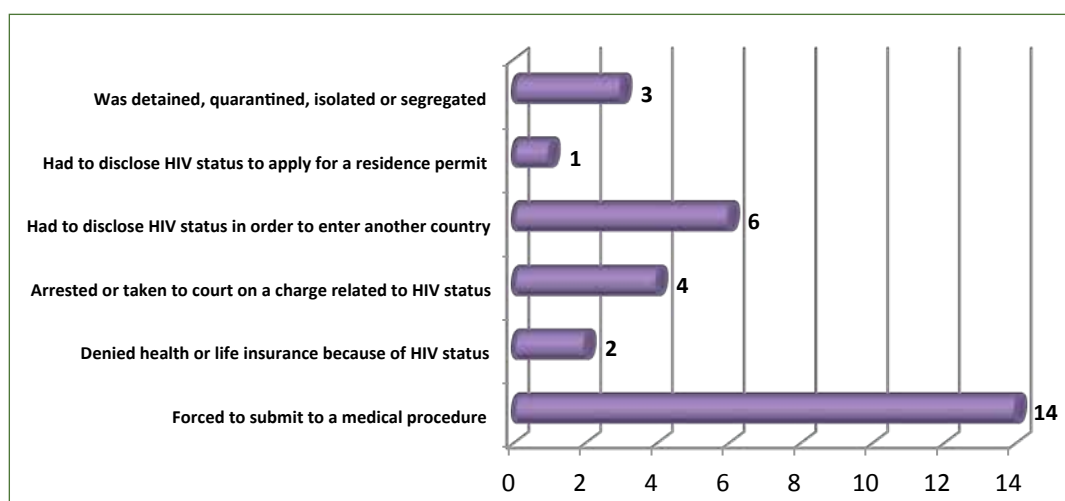
As expected more of the respondents with tertiary level or secondary school level education said they had heard, read or discussed the contents of the policy than those with no formal education. About half of the urban residents (Table 34) who had heard of the National HIV and STI policy had either read or discussed it while only a third of the rural respondents had. This is very encouraging since hearing about the existence of the national policy and even moving further to read or discuss its contents is very important in empowering PLHIV on their rights to living positive lives. However there is still a lot of work to be done to disseminate the national policy so all PLHIV would be aware of the policy in the country that works to their benefit. The general population also needs to be sensitized to be aware of this policy so as to comply and this would help decrease the stigma and discrimination against PLHIV in the country.

The “short code” 1907 set up by CHRAJ in collaboration with NAP+ for PLHIV to report every case of abuse against their rights through SMS text messaging didn’t seem to be familiar with the discussants of all the FGD. The moderators therefore shared it with the members of the FGDs for them to be aware of some of the opportunities and avenues that existed to help them resolve similar issues.

3.5.3. Some forms of violence experienced

Some forms of violations experienced by the respondents in the last 12 months were also assessed and presented in Fig. 17. As many as 14 of the respondents were forced to submit to a medical or health procedure, 6 had to disclose HIV status in order to enter another country and four were arrested or taken to court on a charge related to HIV status.

Figure 17: Forms of violations experienced by the respondents



The respondents were also asked whether their rights as persons living with HIV had been abused in the last 12 months and of the 426 respondents who provided answers for this question 17% (n=73) and 8.2% (n=35) said yes and not sure respectively. About a fifth (20.5%) of those who said their rights as persons living with HIV had been abused said they tried to seek redress. Those who said they had not sought redress were asked why and the responses are presented in Table 35. Almost a third who did not seek redress said it was because of insufficient financial resources to take action, about a fifth said it was because they were advised against taking action by someone and 11 felt intimidated or scared to take



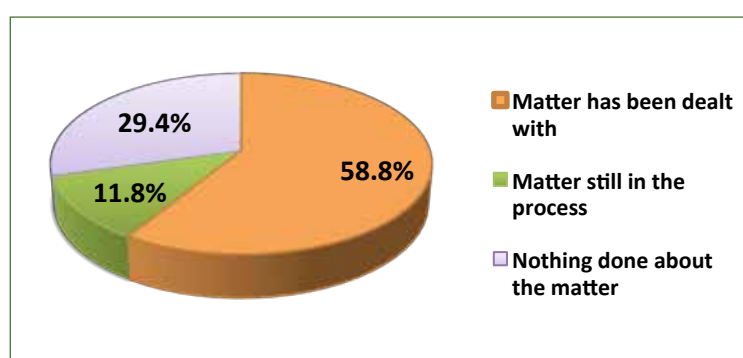
action. The rest indicated that they had no or little confidence that the outcome would be successful or felt the process of addressing the problem appeared too bureaucratic. Policy makers, law enforcement agencies and human rights activists need to improve their advocacy efforts in order to increase the confidence of PLHIV in the services they provide and the system so they can assess the service when their rights are abused.

Table 35: Reasons for not trying to get legal redress for rights abused

Reasons	Frequency	Percent
Insufficient financial resources to take action	17	27.4
Advised against taking action by someone	13	21.0
Felt intimidated or scared to take action	11	17.7
No/little confidence that the outcome would be successful	8	12.9
Process of addressing the problem appeared too bureaucratic	7	11.3
None of the above	6	9.7
Total	62	100.0

The number of respondents who said their rights had been abused in the last 12 months was analyzed by their knowledge of the National policy and their membership of PLHIV network. The results showed that only a fifth and a little above a fifth respectively of the respondents whose rights had been abused were members of PLHIV network or had knowledge about the national policy respectively.

Figure 18: Results of getting government employee to address cases of abused rights



Those whose rights had been abused in the last 12 months were also asked whether they tried to get a government employee to take action against an abuse of their rights as persons living with HIV and all 17 who answered yes, also said the process had begun in the last 12 months. The results are presented in Fig.18. Four of the participants also said they had sought assistance from a local or national politician to take action against similar cases and all of them said the matter had been dealt with.

3.6. HIV Testing and Diagnosis

3.6.1. Why and how respondents got tested for HIV

Testing and counseling are important because of a host of health benefits to the individual, the family and the community, especially with regards to preventing willful or accidental transmission and initiating timely treatment. However, the process of testing for HIV must not infringe on the rights of individuals, yet observations to the contrary are not new in this setting. Thus respondents were asked how/why they happened to get tested for HIV.

As Table 36 shows, the dominant reason for testing was referral due to suspected HIV-related symptoms. This response featured more females (72.9%) than males (27.1%). It was also more of the case for rural (55.8%) than the urban (44.2%). The next major reason mentioned for getting tested was illness or the death of a spouse or partner or a family member. Again, there were gender differentials as this applied to more females (69.9%) than males (30.1%). It is very impressive that only 4 of the respondents said they took the test for employment, because in the national work place policy, HIV test should not be a requirement for employment.



It is a policy in Ghana to routinely offer HIV testing to pregnant women, in order to protect the mother and her unborn child. In 2013, Ghana emerged as the country that had achieved the greatest percentage reduction in new pediatric HIV infections – down an impressive 76% since 2009 (UNAIDS. 2013, “2013 Progress Report on the Global Plan”). This is because the country increased the number of PMTCT centres eight-fold between 2005 and 2011, which in turn increased the proportion of HIV-positive pregnant women receiving PMTCT treatment from 32% in 2009 to 95% in 2012²⁵. This most impressive achievement has also reflected on a dramatic reduction in new child HIV infections from 3, 041 in 2010, to 1, 350 in 2011 to 850 in 2012²⁶. In the current study, more rural women (59.3%) than urban women (40.7%) said they got tested because they were pregnant.

Table 36: Reasons for testing HIV status analyzed by sex and place of residence

Reasons for Testing HIV Status	Sex (%)		Location of Household (%)	
	Male	Female	Rural	Urban
Employment (N=4)	1 (25.0)	3 (75.0)	0(0)	4 (100.0)
Husband/wife/partner/family member tested positive (N=32)	13 (40.6)	19 (59.4)	17 (53.1)	15 (46.9)
Illness or the death of husband/wife/partner/family member (N=113)	34 (30.1)	79 (69.9)	57 (50.4)	56 (49.6)
I just wanted to know (N=45)	22 (48.9)	23 (51.1)	9 (20.0)	36 (80.0)
Pregnancy (N=55)	-	55 (100.0)	33(59.3)	22 (40.7)
To prepare for marriage/sexual relationship (N=4)	1(25.0)	3(75.0)	3 (66.7)	1 (33.3)
Referred by a clinic for STIs (N=32)	10 (31.3)	22 (68.8)	21 (65.6)	11 (34.4)
Referred due to suspected HIV-related symptoms (e.g. tuberculosis) (N=166)	45 (27.1)	121 (72.9)	93 (55.8)	73 (44.2)

There were other respondents who personally initiated the testing process just to know their HIV status. Slightly more females than males personally initiated the testing of HIV status. There was however a wide variation in responses by location. Overwhelmingly, more urban residents (80%) than rural residents (20%) personally initiated the testing of HIV. This is hardly surprising as the former are likely to have more access to testing and counselling services than the latter and are more sensitized through mass media and other channels and awareness creation programmes.

Another reason for getting tested for HIV is the referral by a clinic for sexually transmitted infections. More females (68.8%) got tested for HIV for this reason than males (31.3%). Disproportionately, more rural (66.7%) than urban residents got tested for HIV through referral from a clinic.

The above described trend of reasons for testing ranging from referral due to suspected HIV-related symptoms, illness or the death of a spouse or partner or a family member, because of pregnancy etc. reflected in both the general PLHIV and MSM PLHIV FGDs where the discussants had a mixture of the already mentioned reasons for testing. For the female discussants, the main two reasons for testing were either due to illness or death of a spouse or partner or due to reasons related to child birth/pregnancy.

3.6.2. Mode of Decision Making for HIV Testing

There are several reasons for the testing of HIV status as Table 37 shows. Majority of respondents (65.7%) voluntarily took the decision to be tested for HIV. This is encouraging and may be a pointer to the rigorous campaign for people to check their status. Overall, with respect to *how* the decision to test was arrived at, about 8 percent of respondents reported that their decision to get tested, though self-initiated, occurred under some kind of pressure. About 11 percent were coerced to take the test; while about 16 percent were tested without their knowledge.

²⁵ The Beginning of the End, Tracking Global Commitments on AIDS Volume 2, The ONE Campaign Data Report 2013

²⁶ Ibid



“I was married and lived in Accra but when I got pregnant I came to Tamale to have the baby. At 6 months, my baby developed rashes on the head, body and mouth. Soon afterwards I had diarrhea which was uncontrollable. Since I was unemployed, I asked my step mother for money for transport to seek health care but she refused. Neighbours came to my rescue so I went to the hospital where I was given infusion to reduce the diarrhea. I was told at the hospital that if I agreed to be tested for HIV, all my medical bills would be borne by the hospital but if I refused, I would have to cater for them myself. I was forced to agree. The test results were not made known to me and it was rather a friend who informed me I was HIV positive. There was a reverend mother at the hospital who disclosed my status to others. That Reverend mother was the one who brought me and my baby to Shekina Clinic, a hospice (Hospice care is end-of-life care. A team of health care professionals and volunteers provides it. They give medical, psychological, and spiritual support).

I observed that many people who were positive and had been admitted at the hospice had passed on but I was still alive. I finally got to know that they had taken herbal preparations to treat their condition. I then resolved not to take any such concoctions. The doctor counseled me and put me on special diet and I gradually regained my strength and put on weight” (FGD, Northern Region)

Table 37: How the decision for testing HIV status was made by sex and Location

Decision for testing HIV Status	Sex			Location of household		
	Male	Female	Total	Rural	Urban	Total
Yes, I took the decision myself to be tested (i.e. it was voluntary)	91(74.6)	185(61.5)	276(65.2)	134(64.1)	142(67.3)	276(65.7)
I took the decision to be tested, but it was under pressure from others	8(6.6)	26(8.6)	34(8.0)	19(9.1)	14(6.6)	33(7.9)
I was made to take HIV test (coerced)	9(7.4)	37(12.3)	46(10.9)	21(10.0)	24(11.4)	45(10.7)
I was tested without my knowledge	14(11.5)	53(17.6)	67(15.8)	35(16.7)	31(14.7)	66(15.7)

It is still striking, however, to note that for the nearly two-thirds majority of all the respondents, and even higher (74.6%) in the case of men, the decision to test for HIV was voluntary.

3.6.3. Counselling before and after testing

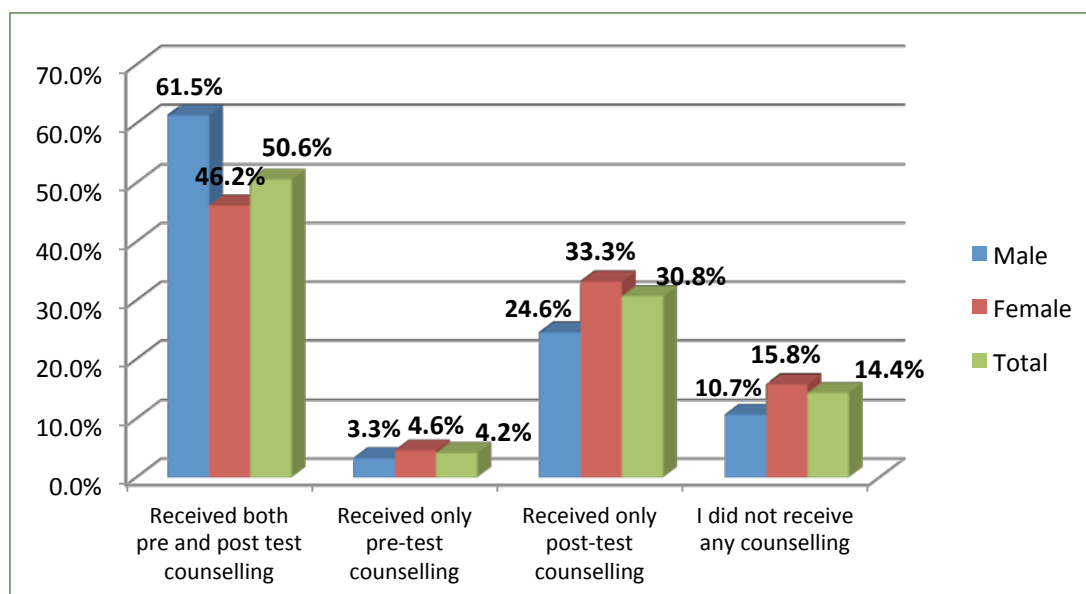
Counselling before and after testing is an important element in the HIV testing process. Pre-test counseling, is to prepare the mind of the patient for the test and to educate them on the implication of knowing one's status. Post-test counselling on the other hand, helps the patient to understand and cope with the results of the test. It also serves as a support for adapting to positive living after the test.

It is evident from the trends captured in Figure 19 that about half of the respondents (50.6%, n=215), received both pre- and post- HIV test counselling; while the rest received only one-time counseling, either before (4.2%, n=18) or after (30.8%, n=131) testing; in addition to 14.4% (n=61) who received no counselling at all. Males (61.5%, n=75) were more likely to receive both pre and post-test counselling than females (46.2%, n=140). Women were however, more likely to receive counselling before (4.6%, n=14) or after (33.3%, n=101) the test or not at all compared to men. The general trend raises concern, though, because almost half of the respondents did not have adequate information before or after the test, which might affect how they received the news of their HIV positive status, how they subsequently lived with the disease and their ability to mitigate its social consequences.

Almost all the discussants for both the general PLHIV FGDs and the MSM PLHIV FGDs reported being well counselled before and after taking the test. However two female discussants of the general PLHIV FGD of Greater Accra Region said they were not well counselled both before and after taking the test. When probed further it came to light that these incidences occurred more than 10 years ago and they attested of the fact that the situation had changed over the years.



Figure 19: Counselling services received during HIV testing by sex



3.7. Disclosure and Confidentiality

PLHIV in most cases feared the consequences of disclosure, thus they tended to conceal their status from people in their social circles. This is because, many of them believe it is the safest strategy to combat stigma and discrimination, drawing vividly on their memory of the way people in their communities reacted negatively to earlier cases of the HIV and AIDS.

3.7.1. Reported pressure on respondents to disclose their HIV status

As highlighted in Table 38 PLHIV indicated that in most instances, they never felt pressured either by individuals not living with the disease like family members or other individuals or by groups living with HIV. There were only slight variations between men and women and place of residence with regards to the pressure that PLHIV feel to disclose their status. About 7.9% (n=32) of the respondents confirmed that their health professionals disclosed their status to others without their prior consent, while 23.4% (n=95) were not sure if information of their HIV status had been shared with other people. Majority of the respondents across gender and location of residence were sure that medical records had not been compromised and were sure it will be kept confidential.

**Table 38: Pressure to disclose HIV-status and perception about confidentiality by sex and Location**

	Sex			Place of residence		
	Male	Female	Total	Rural	Urban	Total
How often did you feel pressure from other individuals not living with HIV (e.g. family members, social workers, non-governmental organization employees) to disclose your HIV status?						
Often	5(4.2)	15(5)	20(4.7)	9(4.3)	11(5.2)	22(4.8)
A few times	7(5.8)	25(8.3)	32(7.6)	20(9.6)	12(5.7)	32(7.6)
Once	2(1.7)	4(1.3)	6(1.4)	2(1.0)	4(1.9)	6(1.4)
Never	106(88.3)	259(85.5)	365(86.3)	177(85.1)	185(87.3)	362(86.2)
How often did you feel pressure from other individuals living with HIV or from groups/networks of persons living with HIV to disclose your HIV status						
Often	4(3.3)	13(4.3)	17(4.0)	4(1.9)	13(6.1)	17(4.0)
A few times	12(10.0)	22(7.3)	34(8.0)	19(9.1)	15(7.1)	34(8.1)
Once	5(4.2)	8(2.6)	13(3.1)	6(2.9)	7(3.3)	13(3.1)
Never	99(82.5)	260(85.8)	359(84.9)	179(86.1)	177(83.5)	356(84.8)
Has a health care professional ever told other people about your HIV status without your consent						
Yes	12(10.3)	20(6.9)	32(7.9)	13(6.5)	19(9.4)	32(7.9)
No	75(64.7)	204(70.3)	279(68.7)	136(67.7)	141(69.8)	277(68.7)
Not sure	29 (25)	66(22.8)	95(23.4)	52(25.9)	42(20.8)	94(23.3)
How confidential do you think the medical records relating to your HIV status are						
I am sure my medical records will be kept confidential	79(69.9)	193(68.2)	272(68.7)	128(66)	143(71.9)	271(69)
I don't know if my medical records are confidential	27(23.9)	72(25.4)	99(25.0)	54(27.8)	43(21.6)	97(24.7)
It is clear to me my records are not being kept confidential	7(6.2)	18(6.4)	25(6.3)	12(6.2)	13(6.5)	25(6.4)

3.7.2. Category of people the respondents disclosed their status to

The decision to disclose one's status especially to family and friends is very important. Patients are usually encouraged to share their status during counseling, especially to their sexual partner(s) so that they can also get tested. Figure 20 presents the categories of people that PLHIV are likely to disclose their status to.

It is encouraging to note that from Figure 20 the highest percentage of respondents, i.e. 76.8% (n=324) disclosed their status to a health care worker. This could be because health professionals in most cases give referrals for testing when they suspect HIV symptoms and also because of the possibility of accessing specialized medical care. Other persons living with HIV were the second largest people that patients disclosed their status to (74.9, n=316) and social workers or counselor (61.5%, n=257). These categories of people are mostly consulted because of their unique position, which makes it easier for them to understand and relate to their situation.

More proportion of the women disclosed their situation to a health worker or social worker than their male counterparts, but in disclosing to other persons living with the disease, there was no difference between men and women. More of the male respondents disclosed their status to their partners than the females. This could be because of women's perceived vulnerability in relationships, thus the fear of losing economic support or abandonment could be a motivation why women are less likely to disclose their status to their partners.

The people in a PLHIV social space are very important because they offer the necessary emotional or psychological support. The low percentages allocated to religious leaders, employers, community leader, co-workers among others indicate the probable fear of discrimination based on either real or anecdotal experiences.

From the FGDs there was a mixture of experiences of being supported after disclosure as well as being discriminated reported by the discussants when they disclosed to the different category of people. Below are some of the comments:



- » *Two people in my church know about my status though I didn't tell them directly. They got to know because they are health workers and happen to be at where I seek health care.*
- » *I'm in a fellowship so I told the leader whose wife is a doctor and they have been very supportive.*
- » *When I told my mum who is women fellowship leader she said nothing but I got to know the news is all over in the church so I've stopped going to the church.*
- » *The other friends and neighbors are not aware of our status. Some of them mistreat us for being MSM and if they should get to know of our HIV status we will face the worst form of rejection.*
- » *My illness started with headache and the doctor requested I go for lab test and they informed me I would have to do the HIV test. It was positive. I said I would die but the doctor embraced me and told me I would be referred to an ART centre. I had gone to the hospital with my grandchild. I informed my second child, who also encouraged me. She has been my support who has gone with me everywhere I went. One of the nurses at the ART site did not treat me well so I sought transfer to another health facility.*
- » *My wife, our child and I tested and we were all positive. I informed my mother and sisters, and their attitude towards me changed. No one wanted to touch anything of ours and my mum did not like the behavior of my sisters. She is dead now but for the 14 years she was our support. My son is 14, on ARV, goes to school, is currently in JSS and he has no problem. There is stigma but I do not allow it to bother me.*

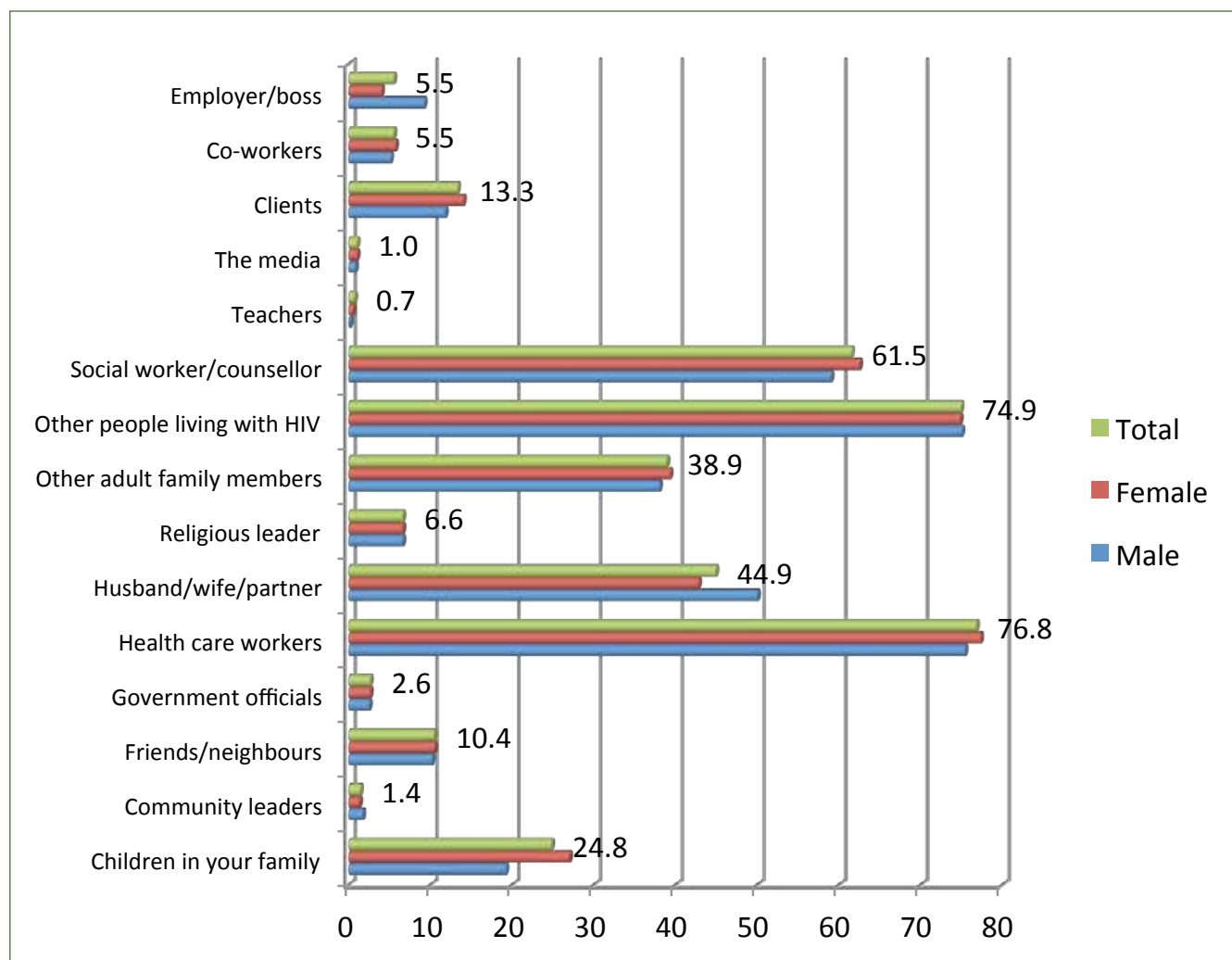
As an agricultural extension worker, we had had the opportunity to attend many workshops on HIV. My child who was a baby died after walking. My wife went to KATH and was tested positive but she did not inform me. I fell ill and lost my hair but my wife still did not say anything to me. Due to my work I do not stay in the same location as my wife. I came to Kumasi on one occasion and met my wife just returned from the hospital. I realized that she carried the bag she took to the hospital everywhere she went and so I became suspicious. She later left it somewhere and I looked through the things and in it and saw her positive results. I left immediately without saying a word and returned to my workplace. I was not aware how I managed to get to my place of abode that night because I was dead drunk.

I re-read all the books I had received about HIV and later went back to Kumasi and requested that my wife should accompany me to KATH to check my status. She was able to take me to all the sections where I needed to go to without any guidance. When I was told to bring a monitor, she quickly volunteered to be my monitor. While waiting for one of my test results, she went off to the Chest Clinic to inform them not to show any signs that they knew her because she would be coming there with me. On reaching home, I asked her how come she was familiar with every section we went to at the hospital and people appeared to know her there also. She then said it was because she had to go through PMTCT when she was pregnant. He then told her about how he got to know her status and asked her if she really loved him. She apologized, saying she had been afraid of his reaction.

I had not informed any member of my family except my son who is a pharmacist. I told my son not to disclose the information. I also informed my Director at work who cautioned me against letting anyone else know. Since my Director was well informed about HIV, there is nothing to fear because he does not allow me to do too strenuous activities. I have not been able to inform my daughter who is very close to me because I know she would not be able to handle it, she is too much of a coward and because she is so close to me I know the news would affect her so much and possibly break her down (Case of a male PLHIV in Ashanti Region)



Figure 20: Category of people the respondents disclosed their HIV status to by sex



Disclosure especially to family members is very important for the emotional support needed by PLHIV. However the level of understanding, knowledge and awareness of the family members about HIV issues is very important. In order not to experience stigma and discrimination the love and cohesion among the family members is also very important. If there are any already existing differences, underlying squabbles and heightened misunderstandings among the family members, disclosure may result in even higher levels of stigma and discrimination. Of this, majority of the discussants of the FGDs indicated that they have not disclosed their status to their family members because they would be insulted and even disgraced in public. A female discussant of the Greater Accra PLHIV FGD shared made this comments “*The husband of my sister who does not know my status usually insult her and insults me too anytime they have misunderstandings. So I can’t tell her otherwise she would tell her husband who would use it to insult me whenever they quarrel. The fact that my mother and my daughter know and they give me support, I am okay*”.



Case of a woman abandoned by her children after disclosing her status, Western Region

One of my painful experiences since being diagnosed HIV positive has to do with one of my children- my oldest daughter. According to her, the sight of me makes her angry. My other children have also stopped coming to me. I live alone. Since I disclosed my status to them, they have all abandoned me. I used to live with them in the same house. But their oldest sister rented an apartment and they all moved to live with her. When I asked my oldest daughter why she gets angry whenever she sets her eyes on me, she said it's because I've grown so lean and she doesn't feel comfortable when her friends are around with me in the house. She is ashamed of me because this is not how I used to be. I used to be quite glamorous and now I look tattered.

As recently as just a few days ago, she repeated that the sight of me disgusts her and though the younger ones haven't said anything, they don't come near me either and it makes me feel so sad because I don't have any children anywhere. I wish I could have people to talk to them. But, it is difficult; I doubt that they would come to my counselor if they were invited. Recently, I told my eldest daughter that my counselor would like to see her and she agreed to go. But she later changed her mind because according to her, the moment anybody comes to the ART site, they also get stigmatized. She is afraid somebody would also say she has HIV.

Disclosure of my HIV status to other family members apart from my children would hurt a lot. I even went to my hometown two months ago and when I got there, people said they had heard that I was living with HIV. In my case, the only problem is the rapid weight loss though nobody has ever gathered the courage to say anything to my face. I have not found any job since they suspected I have HIV. It's very difficult with my condition to find a job.

3.7.3. Voluntary and Non-voluntary Disclosure

Furthermore, majority (76.8%, n=324) of the respondents disclosed their HIV status to Healthcare workers, other PLHIV and Social workers themselves (Table 39). However, voluntary disclosure to non-medical categories of people was relatively lower, and least in the case of Community leaders.

Table 39: Mode of disclosure of HIV status to various stakeholders

Person/Group disclosed to	I told them	Someone told them WITH my consent	Someone told them WITHOUT my consent	They don't know my HIV Status	Not Applicable
Your husband/wife/partner	44.9	6	2.6	11.7	34.8
Other adult family members	38.9	9.7	9.4	34.9	7.1
Children in your family	24.8	1.9	5.9	53.7	13.7
Your friends/neighbours	10.4	0.5	11.1	65	13
Other persons living with HIV	74.9	6.2	5.2	8.5	5.2
Religious leaders	6.6	1.2	3.5	63.4	25.2
Community leaders	1.5	1.2	3.7	64.4	29.1
Health care workers	76.8	11.8	3.6	4.5	3.3
Social workers/counselors	61.5	10.5	1.6	9.8	16.3

More than two-thirds of respondents disclosed their HIV status to their spouses or partners. It is instructive to note, however, that in some cases, respondents' HIV status was disclosed without their consent not only to friends/neighbours (11%, n=46) or other adult family members (9.4%, n=40), but also to Community or Religious Leaders (3.8%, n=16 and 3.5%, n=15 respectively) – Table 39.

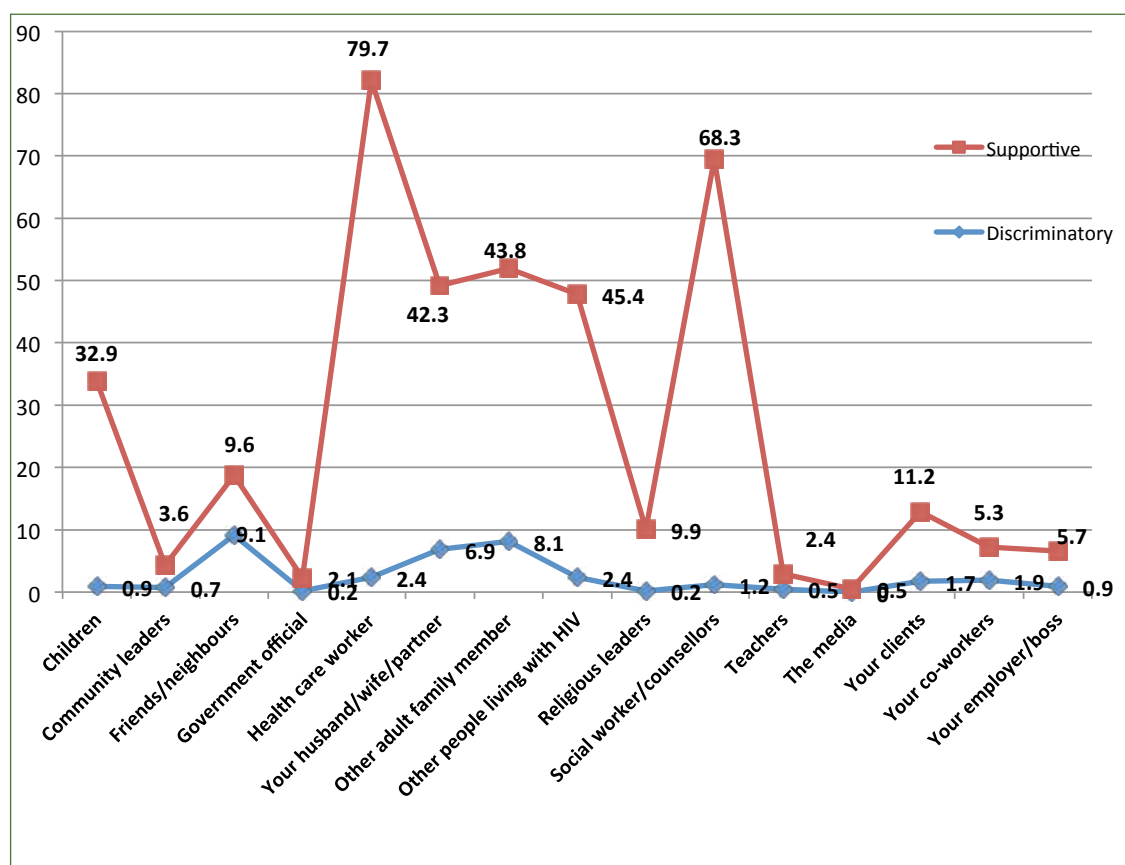
3.7.4. Reactions to Disclosure

Disclosure of HIV positive status could engender two outcomes. One outcome could be positive and may entail increased support, acceptance and kindness, and hence be health-enhancing. The other, could be negative outcome involving neglect, abandonment, blame, stigma etc.



Respondents were asked to state the most common or frequent reaction associated with various categories of people, after they found out they were HIV-positive. Figure 21 presents the findings pertaining to discriminatory and supportive reactions. Clearly, disclosure of HIV status engendered more supportive than discriminatory reactions. Health workers registered the highest reported supportive reaction (79.7%, n=337) followed by a social worker/counselor (68.3%, n=289). This was confirmed during the FGDs where majority of the participants indicated that there used to be discrimination from the health workers but the situation is changing. Some said that the health professionals who have had series of trainings and orientations on HIV and have done this work for extended period of time have become their confidants to whom they are able to share even personal issues with. Close family members such as husband/wife/partner (42.3%, n=178), other adult family members (43.8%, n=185) and children (32.9%, n=139) also showed supportive reactions. Other persons living with HIV also evinced supportive reactions as they accounted for 74.0 percent (n=313).

Figure 21: Percentage of respondents who reported discriminatory and supportive reactions of various categories of the people they disclosed to at first knowledge of their HIV-positive status



Discriminatory reactions were generally low. The highest category of people reported by respondents to have discriminatory reactions was friends and neighbours (9.1%, n=38). This is followed by other family member (8.1%, n=34) and spouse (6.9%, n=29). More female friends and neighbours displayed discriminatory reactions (Table 40). Though there have been extended efforts to completely eliminate stigma and discrimination from health professionals towards PLHIV and their families through several capacity building and awareness creation programmes, several anecdotal reports indicate that there still exist pockets of stigma and discrimination among this group. The fact that there was still some reported level of discrimination by some health providers (2.4%, n=10) in this study which was also confirmed during the FGDs indicates that more efforts need to be put in place to totally eliminate stigma from among the health care providers.



Table 40: Respondents' reports of discriminatory and supportive reactions of various stakeholders at first knowledge of their HIV-positive status

Category of people the respondents disclosed their status to	Discriminatory			Supportive		
	Male	Female	Total	Male	Female	Total
Children	-	1.3	0.9	22.5	37	32.9
Community leaders	-	1.0	0.7	1.7	4.3	3.6
Friends/neighbours	1.7	12.1	9.1	9.2	9.8	9.6
Government official	0.8	-	0.2	0.8	2.6	2.1
Health care worker	1.7	2.6	2.4	79.2	79.9	79.7
Your husband/wife/partner	3.2	8.3	6.9	51.7	38.5	42.3
Other adult family member	6.6	8.6	8.1	45.5	43.2	43.8
Other persons living with HIV	3.3	2	2.4	46.3	45	45.4
Religious leaders	0	0.3	0.2	7.4	10.9	9.9
Social worker/counselors	0.8	1.3	1.2	69.4	67.9	68.3
Teachers	1.7	-	0.5	1.7	2.6	2.4
The media	-	-	-	0.8	0.3	0.5
Your clients	0.8	2	1.7	8.4	12.3	11.2
Your co-workers	1.7	2	1.9	5	5.4	5.3
Your employer/boss	1.7	0.7	0.9	8.4	4.6	5.7

Case of a female PLHIV in Eastern Region about parental disclosure to children

I have been living with HIV for the past 6 years. When I was first diagnosed and my mother got to know about it, she humiliated and disgraced me publicly. And she has been doing that ever since. The reason it doesn't affect me is that people don't believe her because I have been taking my medication and I don't look like someone with HIV. Society's idea of HIV is closely associated with extensive weight loss and being in an almost skeletal state. The more my mother continued to humiliate me, the more she looked like a witch or madwoman to people because I didn't show any symptoms of HIV.

Personally, I wouldn't mind if people got to know that I am HIV positive. But it is the impact it would have on my children for example. Given the general lack of education on HIV, if people get to know - especially the children, they will refuse to come near me or have anything to do with me. However, if public education about HIV has gone down well, Ghanaians in general would have known that HIV is just like any other disease. Like diabetes, hypertension etc. But the way HIV was portrayed earlier engendered fear among the population. What can be done in Ghana to curtail stigma and discrimination is to let everybody understand that HIV is like any other disease. And what we are taught when we go for counselling is, if HIV is well managed, you can live a normal life, people will change their attitudes towards those who live with HIV.

However, due to lack of education, someone who for example needs lorry fare from his parents will be told, "why should we waste our money on you when we know you are going to die soon"? The hurt which results from things like this, is one of the things which make people feel reluctant to even go for medication or support from the health facility. The debilitating effect of HIV on people takes away their ability to work and therefore tend to rely on family support so it becomes difficult if nothing is done to educate people in the family. At least the government has done its part by giving us free access to ARVs and even now we have Health Insurance coverage for most of our drugs. All one needs is money for lorry fare. However, as I mentioned earlier, many people will rather forego their medication than endure family humiliation each time they go and ask for money for transportation. It all boils down to explaining to people that HIV is not a death sentence and encouraging PLHIV to take their medication seriously. If that happens, they will live to their old age/adulthood as ordained by God.



3.8 Treatment

3.8.1 Respondents perception of their health status

Respondents' perception of their own health status matters. In order to understand the perception of respondents about their health, they were asked to rate their current health condition. As shown in Table 41, respondents had a good perception of their health condition, as an overwhelming majority (95.3%) rated good, very good and excellent. Only 4.2 and 0.5 percent of respondents rated their health condition fair and poor respectively. This is a pointer to the high access of respondents to antiretroviral treatment and the success of the ART programme. The number of people who were accessing ARV treatment from the country's 166 service delivery points as of 2012 was 66,504 out of which 63,236 were adults and 3,268 children²⁷. This number is even going to increase further since ARVs have been put on the National Health Insurance list and hence PLHIV are being constantly registered to benefit from the NHIS Local pharmaceutical companies are to benefit from a GH¢50-million facility to produce anti-retroviral drugs (ARVs) in the country. The decision to provide the support, according to the President while delivering his second State of the Nation Address to Parliament on Tuesday, February 25, 2014, constituted one of the major approaches the government was making to reduce the HIV and AIDS infection rate, as well as help save lives.

Table 41: How the respondents describe their health by sex and location

How the respondents describe their health	Sex			Location of Household		
	Male	Female	Total	Rural	Urban	Total
Excellent	37(30.3)	88(28.9)	125(29.3)	65(30.8)	59(27.7)	124(29.2)
Very good	53(43.4)	123(40.3)	176(41.2)	88(41.7)	86(40.4)	174(41)
Good	26(21.3)	80(26.2)	106(24.8)	48(22.7)	58(27.2)	106(25)
Fair	5(4.1)	13(4.3)	18(4.2)	10(4.7)	8(3.8)	18(4.2)
Poor	1(0.8)	1(0.3)	2(0.5)	0(0)	2(0.9)	2(0.5)

3.8.2. Perceived access to ARVs and OIs

As shown in Figure 22, perceived access to antiretroviral treatment is over 94 percent (n=404). It is slightly higher for females than males. Only 3.3 (n=10) and 2.5 percent (n=3) of females and males respectively claim not to have access. More respondents in rural (96.2%, n=203) than urban (93.4%, n=199) households have access to ART. Similarly, there is a high access to medication for opportunistic infections. About 86.1 percent (n=105) of males and 84.9 percent (n=289) of females have access to medications for opportunistic infections (See Figure 23). There is a wide variation by place of residence, as 92.4 percent (n=194) of rural respondents compared to 78.4 percent (n=167) of urban respondents have access to medication to opportunistic infections. As much as 10.4 percent (n=44) claim not to have access to medication for opportunistic infections. This is curious, as urban areas in Ghana happen to be better served with health services in terms of physical accessibility. This may be due to the fact that because of the perception of urban facilities being better equipped and resourced that rural facilities, many clients move to the urban facilities to access services there leaving the urban facilities over- crowded.

Regarding treatment, over 67 percent (n=82) of men compared to 62.7 percent (n=190) of women are currently on medication for opportunistic infections. A much greater percentage (95.1%, n=404) of respondents are on ART. Female is one percentage point higher (95.8%, n=115) than male (94.8%, n=289).

Almost all the discussants for all the 6 FGDs said they were on ARVs with a few on treatments for OIs. According to all of them the availability of ARVs is making PLs look just like everybody else, enough to enable them live normal daily lives able to participate in normal social activities. A few however mentioned occasional drug stock outs which makes it very difficult for them to cope. During such situations the medications are rationed and so they would have to go to the clinic two or four times a month instead of the usual once a month visit and hence increases their expenditure on transport costs. Some also said they are at times referred to other facilities for their medication during stock outs which make it them feel very uncomfortable since they are not sure of how the health workers in the new facilities they have been referred to would treat them. Some even default due to fear of stigma from health workers of facilities other than the ones they are used to when they are referred during stock outs. They therefore said they plead with the government to see to it that there are no shortage of ARVs and the kits and reagents for determining CD4 should always be available.

²⁷ <http://graphic.com.gh/news/health/18323-prez-mahama-announces-gh-50-million-support-for-local-production-of-arvs.html#sthash.IKGlKJ08.dpuf>



Figure 22: Access to antiretroviral treatment, even if not currently taking by sex and location

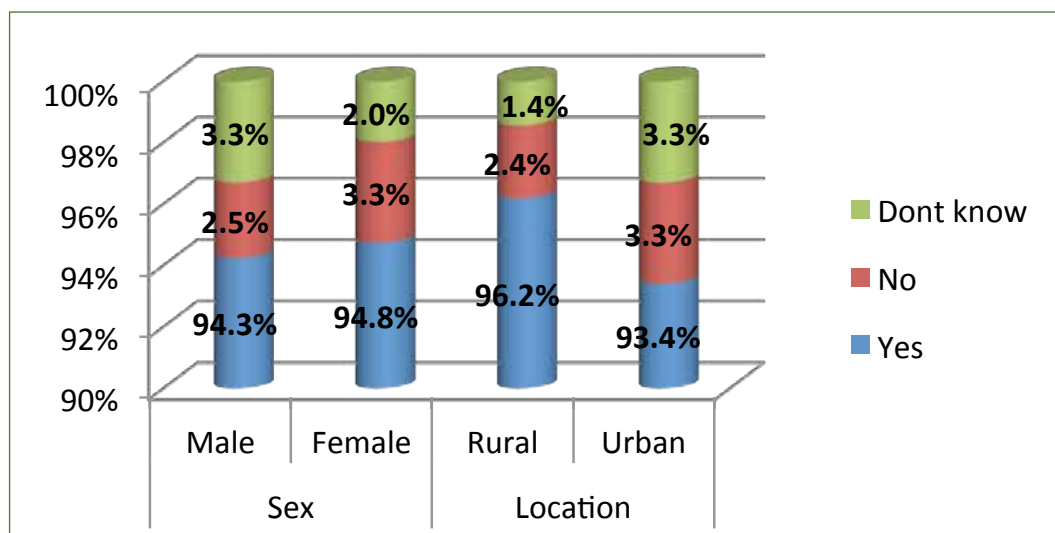
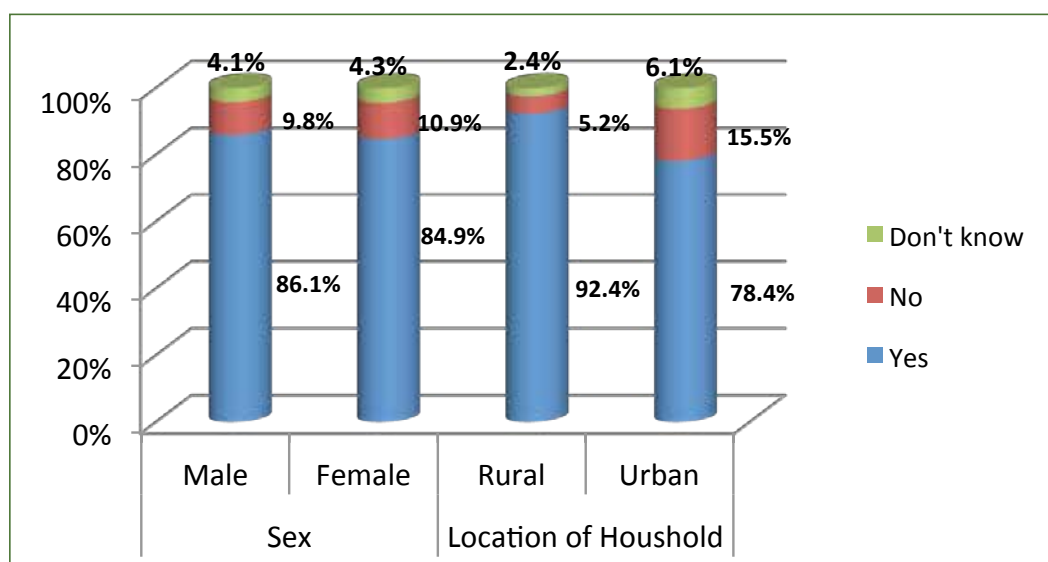


Figure 23: Access to medication for opportunistic infections, even if not currently taking it by sex and location



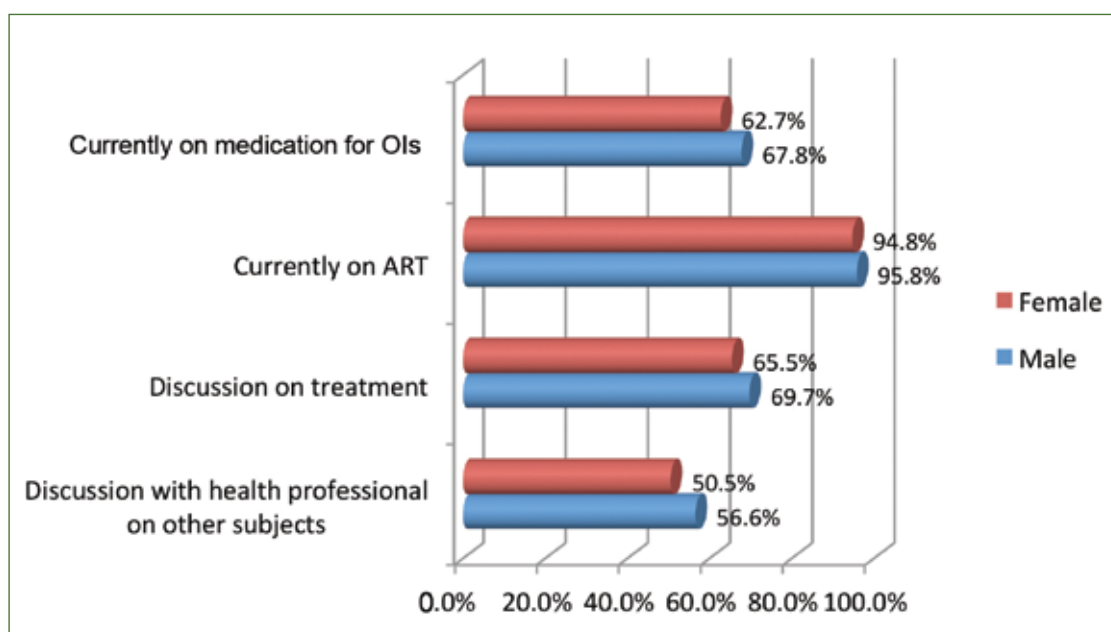
3.8.3. Having constructive discussions with health professionals on health related issues

HIV positive persons at the first knowledge of it are filled with a sense of hopelessness. Even for persons living with HIV for some time, stigma and traducing remarks from people can undermine them. Having a constructive discussion with a health professional on a plethora of health related issues can improve quality of life of persons living with HIV. Figure 24 shows that, about 66.7% (n=284) of the respondents have had a discussion over the past 12 months with a health care professional on the subject of HIV-related treatment option. The variation in terms of gender was minimal (69.7% (n=85) for males and 65.5% (n=199) for females).

Similarly, the percentage of respondents having discussions with health care professionals on other subjects such as sexual and reproductive health, emotional well-being, drug use etc., albeit smaller in percentage terms, also had gender variations. Males accounted for 56.6 percent (n=69) compared to 50.5 percent (n=154) of females having discussions with health professionals on these other issues. Such discussions are pivotal for the emotional wellbeing of persons living with HIV. This was evident during the FGD where for some of the discussants the health facilities tended to be a haven for some of the PLs where they felt very welcomed – due to very cordial interactions with the well trained health professionals who spend time to counsel them on their medication and sometimes even their personal family issues.

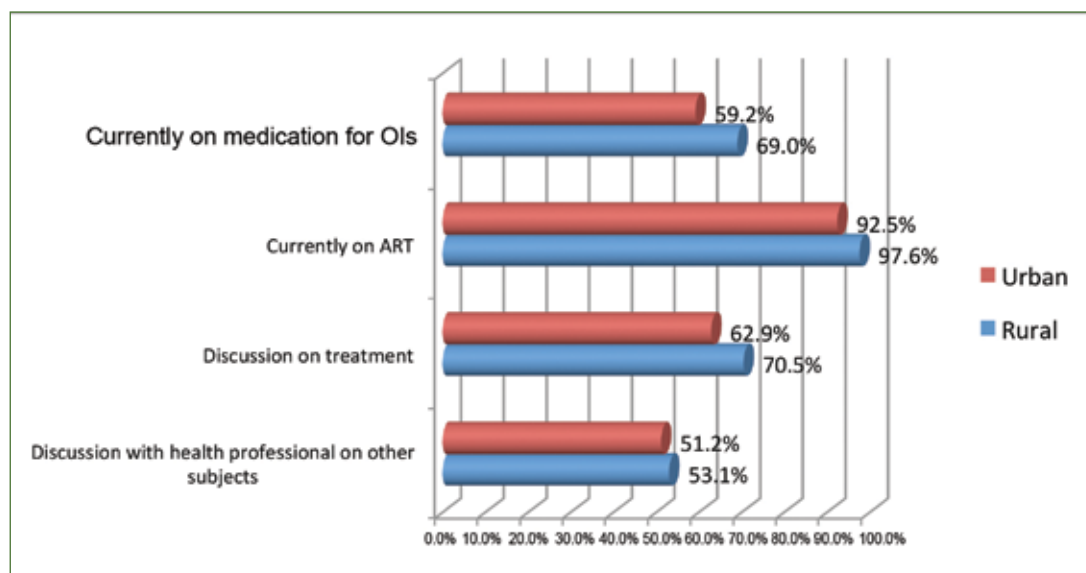


Figure 24: Respondents who were on treatment and have had constructive discussion with health care professionals



As presented in Figure 24, there was spatial differentiation in treatment and discussions with health care professionals. More rural residents (69.0%, n=145) than urban residents (59.2%, n=125) were on medication for opportunistic infections (Fig 25). Also, slightly more rural residents (95.8%, n=205) than urban residents (94.8%, n=196) were currently on antiretroviral treatment. Further, rural residents were about eight and two percentage points higher in constructive discussion with health care professional on treatment and on other subjects respectively.

Figure 25: Respondents who were on treatment and have had constructive discussion with health care professionals by location



3.9 Having Children

A primary goal in public health recommendations for developing countries, is to alleviate overall maternal and prenatal morbidity and mortality with interventions including HIV testing, prevention of mother-to-child transmission and alternatives to breastfeeding where these are available. For this to be realized there is the need for quality sexual and reproductive health care services and respect for the rights of HIV positive mothers. This also entails educating people about reproductive health issues.



3.9.1. Counselling received concerning reproductive health options

It appears counselling about reproductive health options is high among people diagnosed of HIV. Almost 65 percent of the respondents ever received counselling about reproductive health options after being diagnosed as HIV positive. There is minimal gender differential but quite a wide difference in place of residence with more rural (70.9%, n=146) than urban (58.8%, n=124) respondents ever being counseled after being diagnosed as HIV positive (as can be seen in Table 42). Only about 7 percent (n=29) of the respondents said they were advised by a health professional not to have children after being diagnosed as HIV positive. The percentage of respondents was even lower (3.1%, n=13) for respondents who claimed they were ever coerced by a health care professional to undergo sterilization after being diagnosed as HIV positive. This was higher for females (4%, n=12) than for males (0.8%, n=1).

As part of the guidelines for the PMTCT programme, a woman diagnosed with HIV may be advised by a health professional not to have children depending on the viral load and the CD4 count in order not to endanger her life and that of the unborn baby. This therefore might be the reason why some of the respondents reported being advised by a health professional not to have children after testing positive.

Almost one in ten of the respondents also indicated that, their ARV Treatment was provided conditional to the use of certain forms of contraception. Only about 1.3 percent (n=4) of the respondents were forced to terminate their pregnancy after being diagnosed HIV positive. This was in the rural area.

Table 42: Experiences related to reproductive health rights by sex and location

Experiences	Gender			Location of residence		
	Male	Female	Total	Rural	Urban	Total
Ever received counselling about reproductive options after being diagnosed as HIV+	77(64.7)	195(64.8)	272(64.8)	146(70.9)	1224(58.8)	270(64.7)
Ever advised by health professional not to have children after being diagnosed as HIV+	6(5)	23(7.8)	29(7)	16(7.8)	13(6.3)	29(7)
Ever coerced by health care professional into being sterilized since being diagnosed HIV+	1(0.8)	12(4)	13(3.1)	7(3.4)	6(2.8)	13(3.1)
Ability to obtain ART conditional on use of certain forms of contraception	13(10.7)	26(8.6)	39(9.2)	20(9.5)	19(9.1)	39(9.3)

3.9.2. Prevention of mother to child transmission of HIV (PMTCT)

About 22.5 percent of the women said they received ART to prevent mother-to-child transmission. This was slightly higher for the female respondents from urban (24.3%) than the rural areas (21.2%). Majority (57.8%) of the respondents said they did not receive antiretroviral treatment during pregnancy. This is worrying as most vertical transmission is thought to occur during the weeks prior to delivery (one third of cases), or on the day of delivery (two thirds of cases) (Rouzioux et al 2002). For one in five respondents (19.8 percent), it did not apply as they were beyond the reproductive age category. This notwithstanding, only 7.6 percent of the respondents have an HIV positive child/children. During the FGDs almost all the women who participated that did not have ART during their period of pregnancy were those who were pregnant many years ago when PMTCT was not very common in Ghana. This might be the explanation for the low level of PMTCT among the female respondents of the study since Ghana is known to be one of the nations with the most successful PMTCT programme with coverage of about 95% as at 2012²⁸.



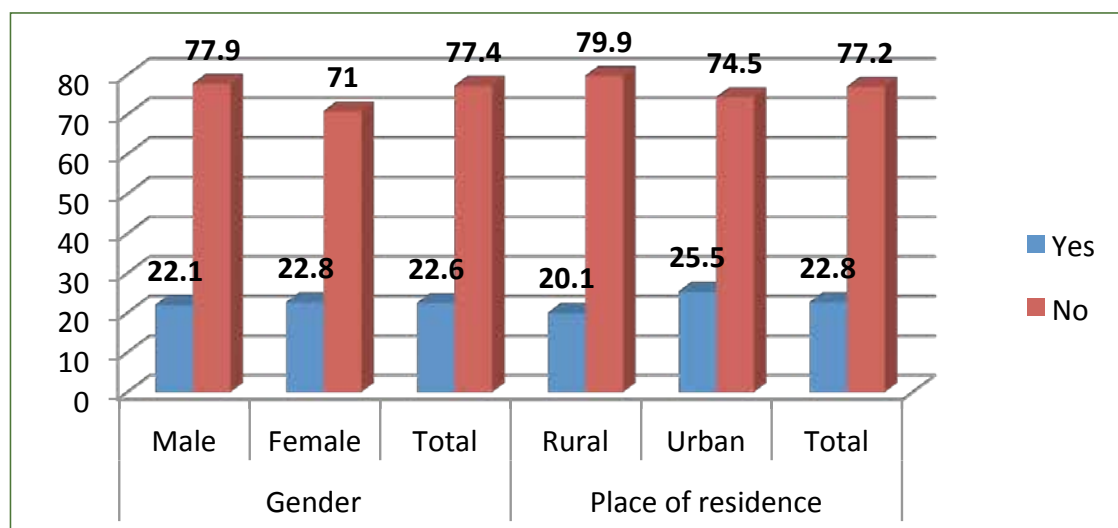
3.10 Effecting Change

3.10.1. Confronting Stigma and Discrimination

Consistent with the tendency to keep their HIV status secret from people in their social circles, and the relative lack of exposure to external stigma and discrimination, majority of respondents, totaling 77 percent (n=328), said they had never confronted, challenged or educated anyone who has stigmatized or discriminated against them (Fig 26). However an average proportion of 23 percent (n=96), have had to do so in both rural and urban contexts. This featured male and female respondents in almost equal proportions. Not confronting stigma and discrimination, however, does not necessarily imply that they have not experienced the phenomenon. In many cases, during the FGDs the PLHIV respondents said they avoided confrontation in order not to attract public attention. A female discussant in Ashanti Region shouted out when this topic came up, by saying

“if you start appearing not to have problems with HIV issues (accepting people with HIV), people would think you are positive and would start stigmatizing against you. I tried to educate a friend with whom I sell in the market one day when we were in a bus going somewhere and issues of HIV were being discussed and she gave certain discriminatory remarks about PLHIV. As soon as I started to educate her on some of the issues because I realised she was ignorant, she asked me whether I was one of them, so I immediately stopped”

Figure 26: Respondents who had confronted, challenged or educated someone who stigmatized and/or discriminated against them



The reasons cited by respondents who **often** confronted, challenged or educated someone who was stigmatizing in the last 12 months were ‘they were being gossiped about’ (34.4%), being verbally insulted (14.6%) and being ‘excluded from family activities’. About a fifth (20.8%) who reacted in like manner **a few times** did so also because they suffered gossip and verbal insults. A total of 26% confronted people who **physically assaulted, harassed or threatened** them, while for 16.6% of respondents in this category, it was the experience of **sexual rejection as a result of their HIV positive status**, which triggered the confrontation at least once (Table 43). As indicated earlier very few of the participants for the FGD said they had confronted people who stigmatized against them in similar ways for fear of being exposed for further heightened levels of stigma and discrimination



Table 43: Respondents who confronted, challenged or educated someone who stigmatized them by the different forms of stigma/discrimination

Social Exclusion	Never	Once	A few times	Often
Exclusion from social gathering/activities	76	10.4	8.3	5.2
Excluded from religious activities	93.8	1	4.2	1
Excluded from family activities	85.4	1	4.2	9.4
Being gossiped about	34.4	13.5	20.8	31.3
Verbally insulted/harassed/threatened	56.3	15.6	13.5	14.6
Physically harassed/threatened	76	15.6	4.2	4.2
Physically assaulted	82.3	10.4	4.2	3.1
Subjected to psychological Pressure by spouse	77.9	6.3	13.7	2.1
Sexual rejection as a result of HIV positive status	78.1	4.2	10.4	7.3
Discriminated against by other PLHIV	85.3	4.2	8.4	2.1
Spouse/family member experience sexual rejection as a result of your HIV positive status	78.1	7.3	9.4	5.2

3.10.2. Organizations from which PLHIV sought help to address stigma and discrimination

Knowledge of where to get support in times of discrimination is vital to reduce psychosocial stress experienced by persons living with HIV. Respondents were therefore asked if they knew or had heard of any organization they go could to for help when they experience stigma or are discriminated against. Table 44 presents the percentage of respondents reporting knowledge of such organizations. About 55.6 percent (n=235) of the respondents said they knew an organization or group that they can go to for help if they experience stigma or discrimination. Slightly more males (59.0%, n=72) than females (54.3%, n=165) have knowledge of such organizations. Also, more urban residents (57.7%, n=123) than rural residents (53.3%, n=112) have knowledge of an organization they can go to for help.

I had to direct a number of my peers to Human rights organizations. For example I recently directed one of my peers to the HRAC, after learning that he was experiencing discrimination. He had been evicted from the room he was renting even though his tenancy had not expired. The landlady took this decision when someone disclosed his MSM and HIV positive status to people in their community. Fortunately, he was helped to access legal aid to fight for his right and he lived there until his tenancy ended. The land lady, after this, stopped discriminating against him (An MSM PLHIV, a peer Educator who was a key informant from Western Region)

Table 44: Organizations or groups that PLHIV know they can contact if they experience stigma or discrimination

Type of Organization	Gender			Place of residence		
	Male	Female	Frequency	Rural	Urban	Frequency
A legal practice	39.7	60.3	58	56.9	43.1	58
Faith-based organization	31.2	68.8	16	50	50	16
Human rights organization	35.4	64.6	99	52.5	47.5	99
International NGOs	54.5	45.5	11	81.8	18.2	11
Local NGOs	46.8	53.2	47	42.6	57.4	47
National AIDS council	52	48	25	52	48	25
National NGOs	47.1	52.9	17	70.6	29.4	17
Network of PLHIV	29.7	70.3	138	47.4	52.6	137
PLHIV support group	27.7	72.3	202	45.8	54.2	201
UN organization	42.9	57.1	7	100	0	7

About 8.3 percent (n=35) of the respondents have sought help from organizations to resolve issues of stigma or discrimination. More females (74.3%, n=26) than males (25.7%, n=9) have sought help from such organizations. More urban (57.1%, n=20) than rural (42.9%, n=15) residents have sought help from such organizations. The most common



reason for seeking help from such organizations was due to verbal assault, which is more a rural phenomenon, gossip and eviction from accommodation. PLHIV support groups and CHRAJ were instrumental in helping resolve such stigma related issues. The issues were resolved by sensitizing the perpetrators on HIV, imposing fines, and warning them.

During the FDGs some of the organizations mentioned apart from the Ghana AIDS Commission and NAP+ were FIDA, DOVVSU, Social Welfare, CHRAJ etc. A few however indicated that they had ever reported similar issue of discrimination to one elder in the town but he did not pursue the case. Thus apart from the formal institutions, the traditional authorities in the communities also need to be involved in the fight against stigma and discrimination by educating and strengthening their capacity on HIV issues.

3.10.3. Supporting other PLHIV and Type of support rendered

One way to enhance emotional wellbeing of PLHIV is for them to extend support to one another. Respondents were asked if they extended support to other persons living with HIV in the last 12 months. Overall, 63.7 percent, (n=272) of the respondents supported other persons living with HIV. Slightly more females (63.9%, n=195) than males (63.1%, n=77) supported others. In terms of rural-urban variation, more urban (69.5%, n=148) compared to rural (57.8%, n=128) residents extended support to others living with HIV in the last 12 months preceding the study. About 87 percent of support rendered went to people who were members of a persons living with HIV support group and/or network.

The dominant type of support extended to persons living with HIV was emotional support (54.6%, n=233). The sex variation of this type of support was very minimal but varied more with place of residence of the respondent. About 60 percent of urban residents extended emotional support, while 48.8 percent of rural residents extended emotional support in the last 12 months preceding the study. The second type of support is for referral services which accounted for about 21 percent, (n= 90) of all the support. More females (22%, n=67) extended this type of support compared to males (19.7%, n=24). More rural respondents (24.2%, n=51) extended referral support compared to urban respondents (18.3%, n=39). The last type of support was physical support, accounting for about 24 percent, (n=101). As it is to be expected, more males (28.7%, n=35) than females (21.6%, n=66) extended this type of support to persons living with HIV in the last 12 months. Disproportionately, higher urban residents (31.5%, n=67) gave physical support compared to rural residents (15.2%, n=32) – Table 45.

Table 45: Type of support provided to PLHIV by sex and Location

Type of support	Gender			Place of residence		
	Male	Female	Total	Rural	Urban	Total
Emotional support	66(54.1)	167(54.8)	233(54.6)	103(48.8)	128(60.1)	231(54.5)
Referral support	24(19.7)	67(22)	91(21.3)	51(24.2)	39(18.3)	90(21.2)
Physical support	35(28.7)	66(21.6)	101(23.7)	32(15.2)	67(31.5)	99(23.3)

From the FDGs and from observations during the field work to conduct the interviews it was very obvious that the “Models of Hope” are playing a major role in making newly infected people overcome suicidal tendencies and instilling hope into them. They also disclose their status to the other PLHIV in order to encourage them to take their medication. One FGD in a very passionate remark said

“A Model of Hope” made me to access drugs and now I am strong so the government should help them”. For the peer educators, a day doesn’t pass without them educating and advising people on HIV/AIDS, positive lifestyle (MSM FGD, Central Region)

Two female participants of the FGD for the Northern Region had these to say concerning how they have helped to effect change in their communities.

The first one said

“I started attending workshops and taught my Mum and family members all I had learnt. This helped them accept my situation. Later, community members said it was alcohol that had made me lose weight. They no longer think I am HIV positive. I met another positive man who told me all about PMTCT and two years later married and I got pregnant and have a baby girl who is negative. Since then I have participated in several training workshops to educate myself and build my capacity to provide counselling and emotional support to other persons living with HIV to be able to deal with their self-stigma and live positive lives”.



The second one added:

“When I got better, I later returned to Tamale to start an Association for HIV positive persons with the former President of NAP+, with support from the Catholic Relief Services (CRS). We were supported to develop proposals and received funding to carry out several awareness creation activities in the communities to educate people on HIV issues. We also provided support and food supplements to other PLHIV from the funding we received. I seized the opportunity to share my experiences as a positive woman with a child who is negative to several women. I started taking ARVs in 2005, 4 years after knowing my status and I feel very healthy living positively”.

3.10.4. Support extended to other persons living with HIV who experienced discrimination

The support extended to other persons living with HIV varied by the various kinds of discrimination. Table 46 shows that the highest support given was for people who were gossiped about (44.1%). About a quarter of support was extended to victims who were verbally assaulted, harassed or threatened. Support was also granted to those who were excluded from social gatherings (10.2%), family activities (11.6%) and religious activities (3%). Support of respondents also went to physically harassed (13.2%) and assaulted (10.2%) persons living with HIV in the last 12 months preceding the study.

Support to persons living with HIV who experience internal stigma is very important as internal stigma is more difficult to discern compared to other forms of stigma. Figure 27 shows proportion of support from persons living with HIV that was given to others who had experienced different forms of internal stigma in the last 12 months. Support varied with the different internal stigma experienced by respondents. More support went to people who blamed themselves (37.5%), followed by those who felt ashamed (33.9%). Support also went to those who experienced low self-esteem (31.1%) and felt guilty (30.6%).

Table 46: Support extended to other persons living with HIV who experienced discrimination

Type of discrimination	Percent
Exclusion from social gathering/activities	10.2
Excluded from religious activities	3.0
Excluded from family activities	11.6
Being gossiped about	44.1
Verbally insulted/harassed/threatened	25.3
Physically harassed/threatened	13.2
Physically assaulted	10.2

Figure 27: Support from respondents to PLHIV by different forms of internal stigma.



Of all the respondents, 53.5%, (n=228) are members of a persons living with HIV support group and/or network. Slightly more females (53.9%, n=164) than males (52.5%, n=64) are members.



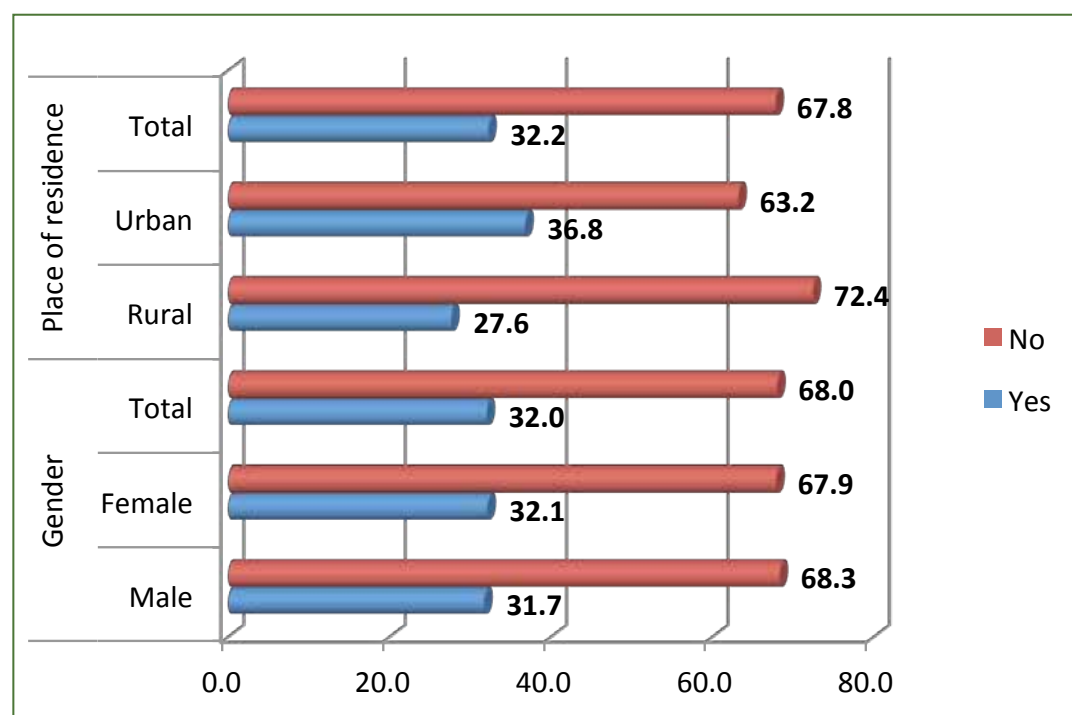
3.10.5. Respondents participation in PLHIV welfare programmes

Respondents' participation in PLHIV welfare programmes or projects appeared much higher, especially in relation to support group membership (56.6%, n=129); although overall involvement across gender registered little variation. In terms of rural-urban differentiation, involvement of PLHIV in urban settings was slightly higher than those in the rural areas (Table 47 and Fig. 28).

Table 47: Respondent involvement in PLHIV support programmes or projects by membership of PLHIV support group

In the last 12 months, have you been involved, either as a volunteer or as an employee, in any programme or project (either government or non-governmental) that provides assistance to persons living with HIV?	Are you currently a member of a persons living with HIV support group and/or network		
	Yes	No	Total
Yes	129(56.6)	6(3.1)	135(31.8)
No	99(43.4)	190(96.9)	289(68.2)
Total	228(100)	196(100)	424(100)

Figure 28: Respondents involvement in PLHIV support programmes or projects by Sex and Location



3.10.6. Involvement of PLHIV in Legislation, policies and guidelines

The study also assessed the role of PLHIV in policy development efforts, and strikingly, respondents living in rural areas reported higher involvement in policy development than their urban counterparts, as illustrated in Figure 29 and Table 48 below. Overall, an overwhelming majority of more than 80 percent, (n=343) said they were not involved in any legislation or policy development effort. It is important for PLHIV to participate in the development of laws and policies that affect their lives in order for them to have knowledge about them as well as them.



Figure 29: Respondent involvement in efforts to develop HIV legislation, policies & guidelines by Sex and Location

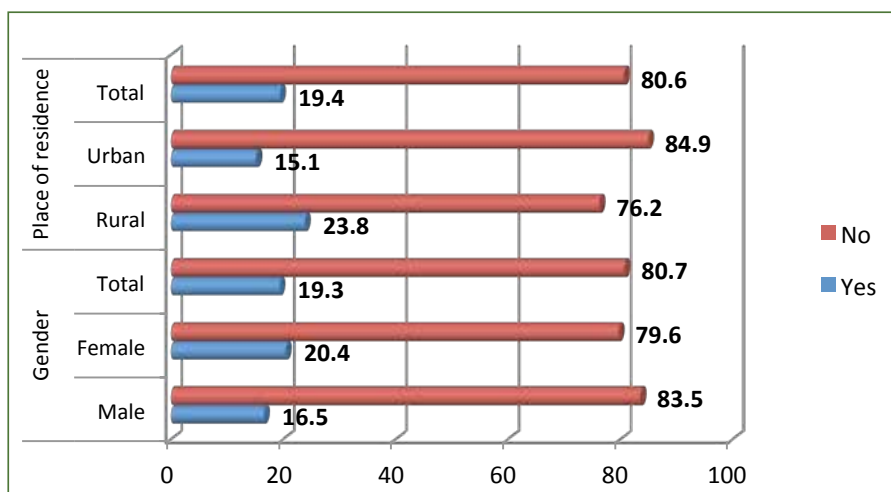


Table 48: Respondent involvement in efforts to develop HIV legislation, policies and guidelines by level of discrimination experienced

Forms of Social Exclusion	Never	Once	A few times	Often	Total (N)
Exclusion from social gathering/activities	92.7	4.5	1.2	1.2	82
Excluded from religious activities	95.1	2.4	1.2	1.2	82
Excluded from family activities	92.7	1.2	2.4	3.7	82
Being gossiped about	53.7	6.1	18.3	22	82
Verbally insulted/harassed/threatened	70.7	9.8	8.5	11	82
Physically harassed/threatened	79.3	13.4	2.4	4.9	82
Physically assaulted	85.4	9.8	2.4	1.4	82

Experience of gossip, verbal or physical assault seemed to be linked slightly with PLHIV involvement in legislation and policy development efforts. Generally, it seems many PLHIV would rather keep a low profile and get on with their lives than risk stirring up any negative reactions whatsoever from members of their communities whiles getting themselves involved in legislation and policy development efforts.

On the other hand, being a member of the PLHIV support group, where they tend to be motivated to fight for their rights, may be fairly strongly associated with participation in policy development efforts. Table 48 shows that 32.6%, (n=74) of the respondents who involved themselves in this regard are affiliated with a PLHIV support group. This is true even though it still leaves out a considerable proportion (67.4%, n=153) of PLHIV support group members who are not involved in policy development.

Table 49: Respondents who were involved in efforts to develop legislation, policies and guidelines related to HIV by membership of PLHIV support group

Involved in any efforts to develop legislation, policies or guidelines related to HIV?	Are you currently a member of a persons living with HIV support group and/or network		
	Yes	No	Total
Yes	74(32.6)	8(4.1)	82(19.3)
No	153(67.4)	189(95.9)	342(80.7)
Total	227(100)	197(100)	424(100)



3.10.7. Respondents' perceived challenges associated with disclosure and confidentiality, testing and diagnosis, access to ARV and having children

At the end of each interview, respondents were asked to mention challenges they might have encountered with regards to disclosure and confidentiality, testing and diagnosis, access to ARV and having children. The purpose was to assess whether there would be variation in responses to the pre-coded questions and these open-ended ones.

a. Disclosure and Confidentiality (Table I in Appendix)

21.8% of the responses were positive, and they typically indicated no problem with disclosure, with a few (5.4%), even associating disclosure with empowerment. Likewise, almost 1 in 10 of the responses indicated that medical records were confidentially kept by health workers so they had no problems with that. On the other hand, majority of the responses (51.5%) emphasized fear of stigmatization as a major challenge to disclosure. To a lesser degree (5.2%), respondents expressed fear or uncertainty about the ability of health workers to keep their records confidential, and 2.8% of the cases expressed regret after status disclosure. On the whole, therefore, 60.6% of the responses categorically expressed challenges in the form of fear or skepticism about disclosure, compared to 25.6% of the respondent expressing no challenge with disclosure. This could become a baseline for measuring subsequent changes in the level of disclosure for future studies.

b. Testing and Diagnosis (Table II in Appendix)

Challenges with testing and diagnosis, like disclosure, were equally striking. Apart from 19% which expressed no challenge with testing, various challenges emerged. The typical challenge highlighted was non-availability of test kits (9.1%). This was followed by fear of being tested positive or being stigmatized. In 4.7% of the cases, how to handle the test results was the major challenge.

c. Access to ARV (Table III in Appendix)

Access to ARV presented no challenges in 21% of the responses elicited. However, 56 of the remaining valid cases highlighted experience of side effects as a major challenge. But the biggest challenge encountered in this regard, was the periodic shortage of drugs (64 responses). Significant reference was also made to the difficulty in adhering to treatment (6.3%). Further attention is drawn to lesser challenges as outlined in Table III in Appendix.

d. Having children (Table IV in Appendix)

The biggest challenge expressed with regard to having children after HIV positive diagnosis, was the fear that the child would become infected (23.2%). This was followed by sheer uncertainty of what might happen to the child, in terms of how to handle the pregnancy and the decision to avoid pregnancy. Overall, challenges associated with having children seemed to outweigh the expression of a positive outlook on the prospect of having children. This is quite surprising, given recent acknowledgement of Ghana's success with regard to PMTCT. However giving the fact that these responses were from the combination of male and female respondents, it is possible that the males don't have much knowledge about PMTCT.



4.0 ESTIMATION OF STIGMA AND DISCRIMINATION INDEX FOR GHANA

Different countries have calculated the S&D Index (S&DI) using different methodologies, scores, indicators etc. Without a consistent methodology to measure stigma and discrimination (S&D) and compute an appropriate index, it is difficult to monitor and evaluate reduction interventions. Although some indices have been developed, no standardized method has been adopted that encompasses all relevant dimensions of S&D²⁹. According to literature the methodology for calculating S&D Index cannot be similar to the methodology followed in the construction of other indices such as the AIDS Program Effort Index (API), the Family Planning Effort (FPE) Index, and the Maternal and Neonatal Program Effort Index (MNPI)³⁰. This is because S&D Index relates to either (1) the community as a whole, (2) providers and/or medical facilities, or (3) persons living with HIV themselves, and hence the S&D Index would have to use a different methodology.

In this instance the researchers grouped the indicators not under the three settings or levels mentioned above but under 7 categories each of which included a composite of stigma indicators corresponding to the defined categories. Thus the Stigma and Discrimination Index was calculated using 33 indicators grouped into 7 categories. These 7 broad categories included Exclusion, Access to work, health and education, feelings of the PLHIV respondents because of their HIV status, things the PLHIV are fearful of because of their status, knowledge of international and national laws and policies that protect their rights, reasons why the PLHIV did not try to get a legal redress for rights abused as well as issues around disclosure.

The 33 indicators chosen representing these 7 categories of stigma and discrimination were as follows:

1. *The 7 indicators representing the different forms of Social Exclusion of PLHIV included exclusion of PLHIV from social gatherings; exclusion from religious gatherings; exclusion from family activities; gossiped about; verbally insulted, harassed/threatened; physically harassed/threatened and physically assaulted.*
2. *The 3 indicators representing forms of enacted stigma included loss of accommodation, loss of job and denial of family planning or SRH services because of HIV in in the last 12 months.*
3. *Seven (7) indicators were used to represent the feelings of the PLHIV because of HIV status (self or internal stigma). These included "I feel ashamed", "I feel guilty", "I blame myself", "I blame others", "I have low self-esteem", "I feel I should be punished" as well as "I feel suicidal"*
4. *Five (5) indicators were used to represent cumulative effect of stigma on the PLHIV (things the PLHIV were fearful of due to their HIV status). These included fear of being gossiped about, fear of being verbally insulted/harassed or threatened, fear of being physically harassed or threatened, fear of being physical assaulted as well and fear of being denied sexual intimacy.*
5. *The 2 indicators to represent PLHIV knowledge about laws and policies at the international and national levels that protect their rights were the proportion of PLHIV who had not heard of the declaration of Commitment on HIV and AIDS and those who had never heard or discussed content of the National HIV and STI Policy.*
6. *5 indicators were also used to represent the reasons why the PLHIV did not try to seek legal redress for rights abused. These included insufficient financial resources to take action, advised against taking action by someone, felt intimidated or scared to take action, no/little confidence that the outcome would be successful and process of addressing the problem appeared too bureaucratic*
7. *The 4 indicators chosen to represent issues stigma issues relating to disclosure were whether the PLHIV felt pressure from other individuals not living with HIV (e.g. family members, social workers, non-governmental organization employees) to disclose their HIV status, whether they felt pressure from other individuals living with HIV or from groups/networks of persons living with HIV to disclose their HIV status, whether a health care professional ever told other people about their HIV status without their consent and how confidential they thought the medical records relating to their HIV status were.*

29 Constructing a Stigma and Discrimination Index: Hopes, Dreams, and Lessons Learned, by Dr. Lori Bollinger, POLICY Project, USAID, March 2006

30 ibid



4.1. Calculation of the Stigma and Discrimination Index

Each of the 33 indicators was given an equal weight/score on a 100-point scale and the scores were averaged to yield the index for each category. To compute the overall S&DI, the average scores for each of the 7 categories were totaled and divided by the number 7 (indicating the average of the total scores across the 7 categories).

As indicated in the table below, the index was categorized into 7 and all categories were assumed to have equal weights. Under each category each of the indicators were also weighted equally in the calculation of the respective categories' score. E.g. under the exclusion category there are 7 indicators and hence the score for that category was computed by totaling the percentages for the seven indicators and dividing by 7. The overall S&D Index for Ghana was therefore calculated to be **18.06%**.

4.2. Interpretation of the Stigma and Discrimination Index for Ghana

While interpreting the S&DI many countries have just used the values to rate the level of stigma in the country as very high, high, moderate, low or very low using a scale of very high (60 points or more), high (45-59 points), moderate (30-44 points), and low (15-29 points) and very low (less than 15 points). These ratings do not determine the outcomes of S&D since the effects and consequences of S&D in a country with a computed index rated very high may be the same in a country rated very low. It must be noted that in the Ghanaian context, though the value is below 20 points (**18.06%**), it does not indicate low levels of stigma. This is because, many of the PLHIV interviewed indicated among other reasons that they had not disclosed because they were afraid of being stigmatized. This in our opinion is indicative enough of the existence of high levels of stigma in the Ghanaian society against persons living with HIV.

Efforts must therefore be put in place measures to ensure that this value does not go up even if more PLHIV become more comfortable to disclose their HIV status to people in their social circles. With the index being 18.06% one would envisage that it would be much easier for Ghana to reach the "Zero Stigma and Discrimination" target if resources are committed to implementing a comprehensive anti-stigma and discrimination strategy throughout the country.

Table 50: Calculation of the Overall Stigma Index for Ghana

<i>Total number of respondents interviewed (N) = 427</i>				
	No. (n)	% = n/427	Internal weight (IW)	Average Index
EXCLUSION (7 indicators)				
Social Gathering	41	9.6%	1/7 = 0.142857143	
Religious gathering	12	2.8%	1/7 = 0.142857143	
Family activities	40	9.4%	1/7 = 0.142857143	
Gossiped about	159	37.2%	1/7 = 0.142857143	
Verbally insulted, harassed/threatened	93	21.8%	1/7 = 0.142857143	
Physically harassed/threatened	44	10.3%	1/7 = 0.142857143	
Physically assaulted	38	8.9%	1/7 = 0.142857143	
Total		100	7	
Average Index for the category = Total/number of indicators				100/7 = 14.3%
ACCESS TO WORK, HEALTH AND EDUCATION (3 indicators)				
Loss of accommodation	51	11.9%	1/3 = 0.333333333	
Job loss in the last 12 months	69	16.2%	1/3 = 0.333333333	
Denied family planning or SRH services because of HIV	18	4.2%	1/3 = 0.333333333	
Total		32.3	3	
Average Index for the category = Total / number of indicators				32.3/3 = 10.8%



FEELINGS BECAUSE OF HIV STATUS (7 indicators)				
I feel ashamed	148	34.7%	1/7 = 0.142857143	
I feel guilty	136	31.9%	1/7 = 0.142857143	
I blame myself	160	37.5%	1/7 = 0.142857143	
I blame others	85	19.9%	1/7 = 0.142857143	
I have low self-esteem	135	31.6%	1/7 = 0.142857143	
I feel i should be punished	33	7.7%	1/7 = 0.142857143	
I feel suicidal	62	14.5%	1/7 = 0.142857143	
Total		177.8	7	
Average Index for the category = Total / number of indicators				177/7 = 25.4%
THINGS FEARFUL OF BECAUSE OF HIV STATUS (5 Indicators)				
Gossip	166	38.9%	1/5 = 0.2	
Verbal insult/ harassment or threats	102	24.0%	1/5 = 0.2	
Physical harassment or threats	64	14.9%	1/5 = 0.2	
Physical assault	53	12.5%	1/5 = 0.2	
Afraid of being denied sexual intimacy	109	25.2%	1/5 = 0.2	
Total		115.5	5	
Average Index for the category = Total / number of indicators				115.5/5 = 23.1%
LACK OF KNOWLEDGE ABOUT LAWS AND POLICIES (2 indicators)				
Not heard of declaration of Commitment on HIV and AIDS by sex and age?	248	58.1%	1/2 = 0.5	
Not heard or discussed content of the National HIV and STI Policy	88	20.6%	1/2 = 0.5	
Total		78.7	2	
Average Index for the category = Total / number of indicators				78.7/2 = 39.4
REASONS FOR NOT TRYING TO GET LEGAL REDRESS FOR RIGHTS ABUSED (5 indicators)				
Insufficient financial resources to take action	17	4.0%	1/5 = 0.2	
Advised against taking action by someone	13	3.0%	1/5 = 0.2	
Felt intimidated or scared to take action	11	2.6%	1/5 = 0.2	
No/little confidence that the outcome would be successful	8	1.9%	1/5 = 0.2	
Process of addressing the problem appeared too bureaucratic	7	1.6%	1/5 = 0.2	
Total		13.1	5	
Average Index for the category = Total / number of indicators				13.1/5 = 2.62%



DISCLOSURE (4 indicators)				
Did you feel pressure from other individuals not living with HIV (e.g. family members, social workers, NGO employees) to disclose your HIV status? Yes	59	13.8%	$1/4 = 0.25$	
Did you feel pressure from other individuals living with HIV or from groups/networks of PLHIV to disclose your HIV status? Yes	65	15.2%	$1/4 = 0.25$	
Has a health care professional ever told other people about your HIV status without your consent? Yes	34	7.9%	$1/4 = 0.25$	
Is it clear to you your records are not being kept confidential? Yes	27	6.4%	$1/4 = 0.25$	
Total		43.4	4	
Average Index for the category = Total / number of indicators				43.4/4 = 10.83%
Overall total				126.42
OVERALL INDEX (overall total /7)				126.42/7 = 18.06%



5.0 CONCLUSIONS

The forgone analysis reveals that PLHIV experience of stigma and discrimination might have been declining in recent times and there are a myriad of individual, and structural factors associated with this apparent trend. However, the evidence also underscores persistence of this twin phenomenon in varying forms and contexts. Attention is hereby drawn to the following key conclusions, which emerged from the integrated analysis of both quantitative and qualitative findings.

5.1 Socio-Demographic characteristics of Respondents

1. *The sex distribution of respondents drawn from all the ten regions reflected the gendered nature of HIV prevalence nationwide, having featured a much higher proportion of female respondents (71.4%, n=305) than males (28.6%, n=122).*
2. *More than 1 in 10 of the respondents belonged to key populations especially MSM and Gay/lesbian or sex worker.*
3. *With regard to age distribution, respondents were mostly aged between 30 and 50 years. Experiences of PLHIV below 15 years were not captured due to the peculiar study design. However, the significant presence of 38 AIDS orphans in PLHIV households was recorded, especially in urban areas, where they constituted almost two-thirds of the total. None of the key population respondents was below 20 years.*
4. *About half (51.6%, n=220) of the general PLHIV respondents and 42% (n=21) of PLHIV in key populations have been living with HIV for less than 5 years. However at least, one in every ten PLHIV interviewed had been living with the condition for 10 years, which sheds light on the country's successful management of HIV through sustained access to ARVs among others resulting in more people living longer, healthier and positive lives with HIV.*
5. *A total of 49.8% (n=211) and 50.2% (n=213) of the respondents were from rural and urban locations respectively with more proportions of the females (51.5%, n=156) residing in the rural locations than their male counterparts. Thus no significant rural-urban differentiation emerged in analysis of the residents of the PLHIV respondents an indication perhaps, of the effectiveness of the nationwide spread of the PLHIV treatment and support services. However more than a half of the KP PLHIV interviewed (65.3%, n=33) resided in urban locations.*
6. *Analysis of PLHIV relationship status revealed striking patterns of more than half of the respondents being in some form of a relationship. High level of intra-PLHIV marriage was revealed among majority of the FGD discussants which they said gives them the social support needed without fear of being stigmatized, discriminated or excluded. Nevertheless, a total proportion of 15.9% of respondents had experienced separation or divorce.*
7. *About 81% (n=347) of the respondents said they were currently sexually active with more proportion of males than females being sexually active.*
8. *Only a third of the PLHIV interviewed had secondary level education or above. The lower levels of formal educational attainment observed among majority of the PLHIV interviewed accords with the general trend among PLHIV in Sub-Saharan Africa. However most of the respondents belonging to KP were literate.*
9. *About a fifth of the respondents were unemployed, with higher levels of unemployment among the females. About a third of the respondents were among the lower income group barely earning the minimum daily wage. However, despite the relatively low socio-economic status observed among respondents in general very minimal trends of food insecurity were reported. Food insecurity was more among the urban PLHIV and those who belonged to key populations.*

5.2 Experiences with stigma and discrimination

1. *The PLHIV respondents avoided all the forms of social exclusion and other forms of discrimination through non-disclosure of their HIV status to individuals and groups outside the health care delivery system with striking majority of respondents, above 85%, on the average, reporting they had "never experienced" any form of HIV-related social exclusion during the 12 months preceding the survey. The worst forms of stigma experienced by the respondents*



however were gossip and verbal insults or harassment, which featured an average of 63% and 79% respectively of the total cases of discrimination reported.

More than one third of respondents experienced these forms of social exclusion at least once regardless of their socio-economic status or gender. Exclusion from religious activities was the least form of social exclusion experienced by the respondents due to lack of disclosure with only 6.6% of respondents having disclosed their status within their religious cycles.

2. Experience of stigma and discrimination was generally observed to be more prevalent among PLHIV in rural than in urban locations. The relatively higher vulnerability of key populations also surfaced in relation to all the forms of social exclusion. Experience of social exclusion among key populations exceeded that of the general PLHIV community by well over 100% on the average, and tended to occur in a more intensified form such as exclusion from social gatherings, family activities and to a greater extent from religious activities, in addition to experience of physical assault. Both the quantitative and qualitative findings attested to this.
3. More proportion of PLHIV respondents who were members of PLHIV network/support group experienced discrimination from their peers than those who were not members. PLHIV who did not belong to key populations also tended to inflict considerable emotional and psychological distress on PLHIV in key populations especially those with homosexual orientations. Non-HIV positive MSM also highly stigmatized against members of their community who had tested positive affecting their access to services.
4. Respondents with no formal or primary level education reported as much as 66.3% of all the reported cases of social exclusion. The highest income groups however reportedly experienced more levels of stigma and its associated forms of social exclusion than the lowest and middle income groups.
5. Low educational attainment appeared to be inversely correlated with experience of physical assault among PLHIV in general. The worst perpetrators of physical assault were members of the households other than the spouses of the respondents. Whilst experience of physical assault in all contexts was higher among females, experience of psychological pressure and manipulation by spouses or partners featured a higher proportion of males than females.
6. A great deal of the self-inflicted or internal stigma experienced by majority of PLHIV bordered on lingering fear and paranoia about being the target of public gossip, which together with verbal abuse/assault or harassment emerged as a fundamental among PLHIV in general and MSM as well as women in particular.
7. Experience of stigma associated with poor nutritional and health status exists within PLHIV networks and tends to hinder access to social and emotional support for victims, including MSM.
8. As much as 86% of the reasons for the experiences of social exclusion were either because of HIV status or both HIV status and another reason. The perceived reason for being stigmatized given by almost a quarter of the respondents was that people are afraid of being infected through casual contact. Religious beliefs and moral judgments were the least mentioned reason.
9. Overall, PLHIV attributed the persistence of stigma and discrimination to ignorance among the general public and inadequate information to transform the effects of the initial negative publicity that engendered fear of being HIV positive.

5.3 Access to work, health and education

1. Experience of discrimination in the contexts of housing, employment, education and healthcare exists, though relatively low on the average. PLHIV attributed these to weak enforcement of policies, and likewise to PLHIV ignorance about the existing policies.
2. About a tenth of the respondents reported they had either been forced to change their place of residence or been unable to rent accommodation at least once in the last 12 months due to their HIV status. This was experienced more among those with urban residence.
3. Sixty nine (16.2%) said they lost their jobs at least once in the last 12 months because of their HIV status. Some of the participants of FGDs said they lost their sources of income because someone went to disclose their status to their clients who stopped patronizing their trade.



4. *Dismissal from educational institution and denial of family planning, reproductive health services and health service in general was very minimal*

5.4 Internalized stigma

1. *Unlike social exclusion, which majority of PLHIV had not experienced during the preceding year, experience of internal stigma, in the form of self-blame and fear of stigma, was more pervasive among respondents. Support group membership helped to mitigate the experience of internal stigma in respect of self-blame, but not in the case of fear of stigma.*
2. *A great deal of the self-stigma or internal stigma experienced by majority of PLHIV bordered on lingering paranoia about being the target of public gossip, which together with verbal abuse/assault or harassment emerged as a fundamental concern among PLHIV in general and MSM as well as women in particular.*
3. *Apart from the negative feelings associated with their HIV status, respondents also reported changes in their behaviours especially with regards to the decision not to have more children (40.8%) and not to get married (24.9%). These two decisions also ranked highest among the KP.*

5.5 Rights, laws and policies

1. *Though knowledge levels about the Declaration of Commitment on HIV and AIDS as well as National HIV and STI Policy were considerably moderate (41.9% and 32.4% respectively) there is still existence of high levels of ignorance about the rights of PLHIV and the policies which work to their benefits. However, the female proportion exceeded that of males in this regard.*
2. *About a fifth of the respondents reported the abuse of their rights as persons living with HIV in the last 12 months and as much as three quarters of them did not seek redress for the abused rights. The reasons were mostly because they had insufficient financial resources to take action, were advised by someone against taking action, had little or no confidence in the process or thought the process appeared too bureaucratic.*
3. *Institutions contacted by PLHIV for redress against their rights abused often provided support. However, the protection of the rights of PLHIV at the community level is woefully inadequate. Knowledge and awareness of the existence of rights, laws and policies among PLHIV might not necessarily translate into application.*

5.6 HIV testing and diagnosis

1. *The dominant reasons for testing were referral due to suspected HIV-related symptoms or illness/death of a spouse/partner or a family member. Few cases of involuntary testing and diagnosis were reported.*
2. *The level of personally initiated HIV testing was higher in urban (80%) than rural areas. Majority of the respondents (65.7%, n=276) voluntarily took the decision to be tested. This is encouraging and may be a pointer to the rigorous campaign for people to know their status.*
3. *Low prevalence of stigma and discrimination associated with testing and diagnoses and this was reported to be indirectly associated with improved medical services for PLHIV; however, shortage of logistics was reported.*

5.7 Disclosure and confidentiality

1. *Disclosure of HIV positive status is evolving in response to the expansion of social capital of PLHIV. This is encouraging, given the potential for enhancing HIV prevention efforts and elimination of stigma and discrimination however the PLHIV respondents in most cases feared the consequences of disclosure and hence tended to conceal their status from people within their social circles. Strategic disclosure of HIV positive status by PLHIV to health care providers and a few 'trusted persons' such as other PLHIV, through effective PLHIV and care-provider collaboration was very high.*
2. *About 8% of the respondents confirmed that their health professionals disclosed their status to others without their prior consent.*



3. *A higher proportion of male respondents disclosed their status to their partners than the females*
4. *Disclosure to health and social workers engendered more supportive than discriminating reactions. Discriminatory reactions to HIV status disclosure were generally low among family members despite low level of disclosure in this context.*

5.8 Treatment

1. *Respondents had a good perception about their health condition as an overwhelmingly 95.3% rated their health conditions as good, very good or excellent. A pointer to the high access to ARVs and treatments for OIs from the country's successful ART programmes especially with the NHIS registering all PLHIV.*
2. *Perceived access to ARVs and medication of OIs was almost universal. While over 90% of PLHIV are on ART, a proportion less than 2/3 of males and a little over 2/3 of female, are on medication for OIs.*
3. *Drug stock-outs and the attempt to avoid stigmatization in their local communities make some PLHIV incur additional travel costs to treatment centers.*
4. *More than two thirds of the respondent said they had had discussions with a health worker on HIV related treatment options in the last 12 months.*

5.9 Having children

1. *Although post-testing counselling about reproductive health options for PLHIV is currently high, almost one-in-ten of the respondents reported that their ARV treatment was conditioned on use of certain forms of contraception.*
2. *7% said they were advised by a health professional not to have children after being diagnosed as HIV positive.*
3. *22.5% of the females said they received ART to prevent mother to child transmission when they were pregnant and only 7.6% of the total respondents said they had HIV positive child/children.*

5.10 Effecting change

1. *Consistent with the tendency to keep their HIV status from people in their social circles and the relative low exposure to external stigma and discrimination 77% said they had never confronted, challenged or educated anyone who stigmatized or discriminated against them.*
2. *With almost 80% of PLHIV avoiding engagement with issues affecting their rights in order not to attract public attention to themselves, the prospect of effecting change would be challenging.*
3. *The evidence suggests that the limited initiatives taken by PLHIV to confront stigma and discrimination, achieved positive results. PLHIV networks and support groups featured prominently in this context; and despite relatively low levels of disclosure to religious leaders reported by PLHIV over 2/3 of those confronted stigma, channeled their grievances through faith-based organizations.*
4. *Overall 63.7% of the respondents supported other PLHIV and the main forms of support were emotional and support for referral services. The roles being played by 'Models of Hope' in making newly infected persons overcome suicidal tendencies and instilling hope into their other peers was highly recommended by the participants of the FGDs.*



6.0 RECOMMENDATIONS

The evidence from the study underscores the fact that PLHIV across the country persistently experience varying forms of stigma and discrimination. Due to a combination of several factors driving these two phenomenon including existing structural factors and social norms, effecting change would require concerted efforts by policy makers, programme managers, service providers, human rights organizations, community leaders, family members and religious leaders as well as active involvement of PLHIV networks to achieve lasting outcomes. The recommendations based on the concluding findings are therefore to draw the attention of specific stakeholders such as policy makers and law enforcement agencies of Ghana, the Ghana AIDS Commission (GAC), the Ghana Health Services (GHS) and National AIDS Control Programme (NACP), NAP+ as well as Civil Society Organizations (CSOs) involved with PLHIV to specific actions they need to take in order to achieve a stigma and discrimination free society.

One key recommendation for all stakeholders is the importance to use the results and information from this study for programming, advocacy efforts and other activities geared at reducing stigma and discrimination against PLHIV so the gains achieved over time can be easily tracked and measured. It might also be insightful to explore the stigma-related experiences of younger and adolescent PLHIV in future studies in the face of the successful ART programmes in the country.

Due to the success of the treatment programme, in increasing the life expectancy for PLHIV, it is very important for development partners, donors and funding agencies not to relent in releasing funding to support the programme so that PLHIV can live healthy and positively.

6.1 Policy makers and law enforcement agencies

- » *Urgently strengthen and enforce policies and legislation to address all the pockets of the forms of stigma and discrimination against PLHIV. These policies that work to the benefits of PLHIV (especially the National HIV and STI Policy) also need to be disseminated urgently among all PLHIV in order for them to be aware of their existence. This would also enable PLHIV to be aware of their rights as persons living with HIV. However the effective dissemination of the National HIV and AIDS policy should be more widespread and should not only target PLHIV networks but also the general public, including educational institutions. The policy document could be reduced to pocket sized abridged versions translated into the local languages and with pictures to depict the information so it can easily be understood even by those with no formal education and those that are not literate.*
- » *Ensure the increased participation of PLHIV from all levels in general and the grassroots in particular in the development of future policies and laws that are intended to benefit PLHIV to foster better ownership of those policies by PLHIV.*
- » *Reduce the time and cost involved in the processes in addressing reported cases of abuse in order to increase the confidence of PLHIV in the system so they can access the services in times when their rights are abused.*
- » *Educate formal and non-formal employees on the existing national workplace policy for them to comply and the policy needs to be enforced to ensure PLHIV don't suffer loss of their jobs and sources of income on account of their HIV status.*
- » *Clearly define the rights of PLHIV to decent accommodation in the national housing policy and this must be made known to landlords/landladies as well as the PLHIV community. Enforcement of these guidelines and policies should be constantly monitored by the rent control board of the nation.*
- » *Increase efforts on prevention and management of gender-based violence, legal reform and enforcement of laws and mechanisms protecting PLHIV in particular from gender-based violence, harassment etc.*

6.2 Ghana AIDS Commission (GAC)

- » *To control new infections among the general population and key populations in particular GAC should sustain its programmes on prevention using effective behavior change communication strategies that have proven to be effective in targeting the general population and non-HIV positive key populations, especially MSM and sex workers.*



- » *Advocacy strategies should underscore the fact that at least one in every ten PLHIV has survived the condition for a decade. A documentary dubbed “A decade with HIV” could therefore be developed to show-case the success stories of effective HIV treatment in Ghana. This will also enhance mobilization of funds locally to sustain access to ARVs as well as putting a positive face to being positive with HIV to disabuse the minds of the populace from the initial fear associated with being HIV positive. This will help reduce to a great extent the stigma and discrimination against PLHIV in society and also encourage more people to voluntarily take the test to know their status and PLHIV to disclose their status.*
- » *Avoid shortage of ARVs, testing kits and logistics for determining CD4 count as much as possible since this creates a lot of panic amongst PLHIV especially when they have to be referred to other facilities to access these services due to fear of being stigmatized or discriminated. In this regard the President’s effort to ensure adequate and constant supply of the ARVs in the country by providing local pharmaceutical companies with the funding to commence local production of the drugs is highly commended.*
- » *The existence of some level of food insecurity among PLHIV is very alarming therefore programs that provide food supplements need to be continued and measures should be put in place to ensure their sustainability.*
- » *Interventions targeting PLHIV should factor in their low literacy and income levels; and as much as possible, programmes should be designed to ensure minimal cost to PLHIV. Though food insecurity was not too high the existence of some level of food insecurity among PLHIV is very alarming and programmes that provide food supplements need to be continued to support the group of PLHIV who have challenges in providing adequate food supply for their households. This will help improve the nutritional status of the affected PLHIV in order not for them to appear lean to attract any form of stigma and discrimination from the society in general or from their peers in particular.*
- » *Strengthen the “Models of Hope” concept through provision of logistics e.g. support to cover the cost of transportation to and from the ART sites and material incentives to motivate them to continuously provide the needed moral and psychosocial support to their peers especially those newly diagnosed so they would overcome their internal fears.*
- » *Include HIV-related stigma and discrimination indicators as part of the M&E system in the national HIV response to monitor and evaluate progress over time.*

6.3 Ministry of Health, Ghana Health Services and National AIDS Control Program (NACP)

- » *Ensure access, availability, sustainability, and quality of treatment and care services (e.g. availability and access to timely and appropriate antiretroviral therapy, diagnosis and treatment for Hepatitis B and Cervical and Prostate cancer screening).*
- » *Ensure access, availability, sustainability, and quality assurance of psychosocial well-being services (e.g. mental and emotional health services, counselling services and support groups).*
- » *Sustain the campaign for people to know their status however health workers that perform the test should be constantly monitored to ensure they adhere to the guidelines by providing proper pre- and post- test counseling. Sustained supply of testing kits to regional and district hospitals is very critical in this regard since the absence of the kits is resulting to only diagnostic testing defeating the success chalked by the “know your status” campaign.*
- » *Ensure confidentiality of HIV-positive status of PLHIV and provide friendly and enabling environment/conditions for safe, voluntary, and beneficial disclosure in order to encourage and increase the levels of strategic disclosure of HIV positive status by PLHIV to health care providers through effective PLHIV and care-provider collaboration. This may eventually evolve into PLHIV becoming more comfortable to disclosure to family members, friends, religious leaders and other possible ‘trusted persons’ in order for more PLHIV to receive support from their social circles.*
- » *Intensify public education in general and couples counselling in particular about the improved medical facilities available for HIV and AIDS management and the enhanced longevity for PLHIV. This would help reduce the rate of divorce especially among discordant couples and psychological pressure exerted on PLHIV in general by their spouses/partners.*



- » *Intensify education among the general public in general and PLHIV in particular (especially the males) about availability of PMTCT programme that has proven to be successful to address the high level of fear of having children among PLHIV.*
- » *Regularly evaluate, re-train and enhance the HIV management skills for health professionals especially those in low capacity areas. This is very critical to help improve their skills in providing non-judgmental, unprejudiced health quality health services in general and family planning, sexual and reproductive health services in particular to HIV positive clients.*
- » *Provide health-provider training on sexuality, gender, stigma, discrimination and gender-based violence*
- » *Uphold the Sexual and Reproductive Health rights of PLHIV by as much as possible actively involving them in reproductive decision making. Implement strategies to constructively engage men in reproductive and sexual health*

6.4 NAP+ Ghana

- » *Implement educational programmes within PLHIV networks and support groups on how important it is not to stigmatize against a peer PLHIV regardless of the physical appearance, economical status or sexual orientation to enable all PLHIV benefit from relevant support services.*
- » *Enhance access to psycho-social support by encouraging PLHIV to join a network or support group where their fears and feelings could be shared in order for them to get help from their peers who have gone through similar experiences but have been able to overcome and living positively. Build capacity of more PLHIV to provide psycho-social support to their peers*
- » *Increase advocacy efforts and empower PLHIV networks by improving their capacity to seek redress for rights abused. This would deter people from abusing the rights of PLHIV especially when they are made to face the law.*
- » *Empower PLHIV to embrace and lead the meaningful involvement of people living with HIV in programmes and activities that concern PLHIV at all levels through:*
 - *positive leadership, participation in policy dialogue and advocacy*
 - *Mentoring of future leaders including women and young PLHIV*
 - *Peer support groups (adolescents and above 50's)*

6.5 Civil Society actors involved in the HIV response

- » *Build capacity of policy makers for policy monitoring and public accountability as well as the active involvement of all stakeholders in policy dialogue.*
- » *Build advocacy capacity of organizations involved in PLHIV and networks of PLHIV to enable them to actively:*
 - *Campaign for policy change in areas where there are gaps*
 - *Mobilize the society and engage the community for social change*
 - *Mobilize resources for networks and associations of PLHIV to implement their activities*
 - *Facilitate networking opportunities*
 - *Link to other social justice and development movements or organisations*
- » *Educate and improve the literacy of PLHIV on Family planning, Legal and rights, building of self-esteem and confidence. Increase advocacy efforts and empower PL networks by improving their capacity to seek redress if their rights are abused.*
- » *Engage in legal advocacy and activism for women's rights, rights for men who have sex with men and networking opportunities.*



- » *Intensify education among the general public in general and PLHIV in particular (especially the males) about availability of PMTCT program that has proven to be successful to address the high level of fear of having children among PLHIV.*
- » *Develop and implement age-appropriate and HIV-specific sex and relationships education for children and adolescents born with HIV.*
- » *The mere presence of some form of religious exclusion is indicative of the fact that there is still a lot of advocacy work to be done among religious leaders and the congregation to disabuse their minds from any negative moral behaviours associated with being HIV positive. Thus there is also the need to intensify efforts to build capacity of religious and traditional leaders for community mobilization and advocacy against all forms of social exclusion as well as strengthening solidarity among PLHIV for collective action.*
- » *Apart from spouses or partners of PLHIV, the next important groups to be targeted with anti-stigma related messages are members of PLHIV households who need to be educated on the need for them to provide the much needed emotional support for PLHIV.*

6.6 Best Practices and Lessons Learnt

1. *The risks for social harm associated with breach of confidentiality in the context of HIV research can be minimized through the direct involvement of PLHIV in HIV research.*
2. *Peer educators facilitate access to key populations and other hard-to-reach target participants (e.g. the middle class), and thus forge a vital link between researchers and members of the PLHIV community, among whom concerns about trust and confidentiality may not only be of ethical interest, but also essential to safety and well-being.*
3. *Well intended programmes designed to improve the quality of life of PLHIV could inadvertently fuel stigma and discrimination, unless properly integrated into existing facilities.*
4. *Apparently declining prevalence of stigma and discrimination could be misleading in view of the fact that it could be a function of strategically selective disclosure borne out of fear, rather than actual reduction of the phenomenon.*



APPENDIX – CHALLENGES ASSOCIATED WITH DISCLOSURE, TESTING, ARV AND HAVING CHILDREN

1. Disclosure-related challenges

Challenge	N	%	Challenge	N	%	Challenge	N	%	Challenge	N	%	Challenge	N	%
No problem with disclosure	61	14.3	Not sure records are confidentially kept at the centre by health workers	22	5.2	Shy to disclose my status	5	1.2	I believe it has been kept confidential by the health workers	1	0.2	Regretted disclosing my status	12	2.8
Disclosure was helpful to me/empowered me	23	5.4	I did not disclose my status but it has been known	1	0.2	The fear of being stigmatized	1	0.2	I don't think my status has been disclosed to anyone	1	0.2			
Easy to disclose to close relatives but not outsiders	9	2.1	Health worker disclosed my status without my consent	4	0.9	Unable to disclose because i don't trust anyone	34	8	I believe in the safety of the records at the centre	1	0.2			
						Unable to disclose because of fear of stigma and discrimination	173	40.5	Records are confidentially kept at the centre by health workers	39	9.1			
						If you disclose you will be stigmatized especially your neighbours	1	0.2	Records are confidentially kept at the facility	1	0.2			
						No need to disclose my status	2	0.5						
						Fear my relatives cannot handle it if I disclose my status	1	0.2						
						Fear stigma but I disclosed my status anyway	2	0.5						
						For the fear of being stigmatized I travel for treatment else where	1	0.2						
Total	93	21.8		27	6.3		220	51.5		43	9.9		12	2.8



III. ARV related Challenges

Challenge	No.	%
No problem	89	21.1
Feel stigmatized going for drugs	1	0.2
Periodic shortage of drugs	64	15
The people talk a lot on how to use the drugs	1	0.2
Delay in giving out the drugs at the centre/It takes too long a time to get on the drugs	12	2.7
Not on ARV	3	0.7
Changing the drugs without adequate education on them	10	2.3
Cost of transportation	10	2.3
A monthly charge of GHS 5.00 for the drugs	13	3
Experience some side effects	56	13.1
Difficulty in adhering to treatment	27	6.3
Other	8	1.9
Total	294	68.8

VI. Challenges related to having children

Challenge	No.	%	Challenge	No.	%	Challenge	No.	%
Fear the child will be infected	99	23.2	No problem	1	0.2	Health workers feel reluctant to help HIV mothers especially during labour	4	0.9
Fear will die and leave the child behind	1	0.2	No problem	41	9.6	Inadequate education on PMTCT	3	0.7
Not advisable to give birth in this state	1	0.2	No problem with the help of PMTCT	1	0.2	Other	6	1.4
Not sure I can handle it	21	4.9	Possible to give birth normally	1	0.2			
Planned not to give birth again	56	13.1	Possible to give birth normally with PMTCT	69	16.2			
Fear the child will die	2	0.5						
Total	180	42.1		113	26.4			



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