

**STUDY REPORT**

**NATIONAL SURVEY**

**HIV & AIDS RELATED STIGMA AND DISCRIMINATION INDEX**

**South Central Somali, Puntland, Somaliland**



April 2017

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## Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal Care
ARVs	Anti Retrovirals
BCC	Behaviour Change Communication
CASCO	County AIDS STI Control Officer
CBOs	Community-Based Organizations
CCC	Comprehensive Care Centre
CSO	Civil Society Organization
FGD	Focus Group Discussion
FSW	Female Sex Workers
GFATM	Global Fund to Fight AIDS, Tuberculosis and Malaria
GIPA	Greater Involvement of People Living with AIDS
GNP+	Global Network of People Living with HIV
GP	General Population
HCP	Health Care Providers
HCT	HIV Counseling and Testing
HIV	Human Immunodeficiency Virus
ICW	International Community of Women Living with HIV and AIDS
IDU	Injecting Drug Users
IEC	Information Education Communication
IPPF	International Planned Parenthood Federation
KII	Key Informant Interviews
MARPS	Most at Risk Populations
MOH	Ministry of Health
MTCT	Mother to Child Transmission
NGOs	Non-governmental Organizations
OVC	Orphans and Vulnerable Children
PLHIV	People Living with HIV
PMTCT	Prevention of Mother to Child Transmission
SCS	South Central Somali
S&D	Stigma and discrimination
SDI	Stigma and Discrimination Index
STD	Sexually Transmitted Diseases
STI	Sexually Transmitted Infections.
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV and AIDS
UNICEF	United Nations Children's Fund
VCT	Voluntary Counseling and Testing
WHO	World Health Organization

## **Acknowledgement**

The Stigma Index Study was undertaken with support from diverse stakeholders at the Regional, National and Sub National levels. It involved extensive consultations with PLHIVs, government stakeholders, Civil Society Organizations (CSOs) and Communities. We appreciate the support and input provided by the PLHIVs, General Community, Religious Leaders, the respective AIDS commissions and Ministry of Health Officials during this process. The study was undertaken in South Central Somali, Puntland and Somaliland during the period February- March 2017.

We would like too, to acknowledge UNICEF for providing technical support and leadership in the process. The study was undertaken with financial support from the Global Fund. The study was led by an independent consultant, Mr. Vitalis Akora, as the Principal Investigator, supported by UNICEF staff. Data collection was undertaken by a team of Research Officers and Enumerators drawn from South Central Somali, Puntland and Somaliland. Majority of the Enumerators were PLHIVs and the field supervisors were MOH Officials at various levels. The ART Center Coordinators provided the PLHIV lists for sampling and coordinated participants' mobilization. We hope that the report goes a long way to provide evidence for HIV/ AIDS programs and policies in Somali.

## Executive Summary

### Introduction

World leaders in the UN high level meeting in 2001 committed to achieving universal access to HIV prevention, care, support and treatment. This was again reaffirmed during the high level meeting in June 2011. The Global leaders recognized that full realization of all human rights and fundamental freedoms for all is an essential element in the global response to the HIV epidemic, including in the areas of prevention, treatment, care and support. The leaders also recognized that addressing stigma and discrimination against people living with, presumed to be living with or affected by HIV, including their families, is also a critical element in combating the global HIV epidemic.

HIV-related stigma and discrimination are more increasingly recognised as a huge barrier to combating AIDS in sub-Saharan Africa and elsewhere. Stigma and discrimination are a health and human rights issue. They pose obstacles to achieving universal access to prevention, treatment, care and support. Stigma and discrimination are associated with lower uptake of preventive services, testing and counselling; reduced and delayed disclosure of HIV sero-status; and postponing or rejecting care, seeking healthcare services outside one's community for fear of breach of confidentiality.

In Somali, the level of stigma is presumed to be very high, and likely to prevent people living with HIV from coming out openly to seek health services. There has however been no large scale stigma and discrimination study, undertaken in Somali.

The overall objective of this study was to generate strategic information on HIV related stigma and discrimination to guide interventions that address HIV related stigma and discrimination and policy frameworks. The results from the study are expected to provide a powerful advocacy tool to address HIV related stigma and discrimination.

### Specific Objectives

1. To study and document the levels of various forms of HIV-related stigma and discrimination against PLHIV, focussing on the individual, family and community levels.
2. To identify and document factors and manifestations that perpetuate or mitigate stigma associated with HIV and AIDS.
3. To document the effects of stigma & discrimination on HIV prevention, treatment care and support services
4. To compute a quantitative stigma and discrimination index for the study area
5. To draw conclusions from the study and make recommendations to support advocacy programs and policies that will enhance the quality life for people living with HIV.

### Methodology

The study was a cross-sectional survey using mainly quantitative methods. The quantitative survey approaches sought to measure the overall stigma index and indices for diverse forms of stigma. Qualitative approaches were also used to explore the various forms of stigma by population segments and by region. The study was conducted in the entire Somali. The study area was first stratified into three: South Central Somali (SCS), Puntland and Somaliland. Proportionate samples were derived from each of the areas. All respondents in the quantitative survey were sixteen years old and above and who received HIV care and treatment at registered ART Centers. The ART Centers were selected randomly for inclusion in the study. A total of 750 PLHIVs took part in the quantitative study. Qualitative data collection methods included Key Informant Interviews (KII) and Focus Group Discussions (FGDs) and targeted the general population, PLHIVs, and stakeholders from the Civil Society Sector, MOH Management Teams, AIDS Commissions, PLHIV Networks, Health Service Providers at the ART Centers and in other Health Facilities that were non ART Centers. The study ensured client privacy and confidentiality of client information. Informed consent was obtained from each participant before the start of the interviews. The study sought and obtained approval from the government authorities in SCS, Puntland and Somaliland prior to the survey. In each case, the comments provided by the relevant Authorities were integrated into the protocol prior to its implementation.

## Limitations of the Study

HCT uptake in Somali is low. It is generally assumed that a large proportion of the Somali population has not been tested for HIV and hence not aware of their serous status. The sample was drawn entirely from the clients receiving services at the ART Centers. To some extent, therefore, the sample may not have provided accurate representation of the persons living with HIV (PLHIV) in Somali. On the other hand, Pilot testing of the tool was not undertaken and mock interviews were used instead. A few variables were therefore not well captured during the data collection. A pilot exercise could have identified these challenges.

## Key Findings

### Demographic information

The mean age of the study participants, in years, was 38.8, with a minimum of 16 and maximum of 80. The age Categories represented in the study included: 16-24 (6.1%); 25-29 (14.0%); 30-34 (16.0%); 35-49 (48.7 %); >=50 years (15.2%). The respondents included 62.4% (468/750) female population and 37.6% (282/750) males. Against 59.7% (448/750) of the respondents who had not attended school, 38.4% (288/750) reported they had attended school. Majority of the respondents were either not working (60.3%) or self-employed (20.4%), while only 15.6% were in salaried employment. Almost all the Respondents had been in marriage at one point in their lives (96.0%; (720/750)) against 4% (30/750) who had never been married. The mean age of marriage for the male population was 23.5 years while that of female was 18.1 years. Table 2 provides the details on age at first marriage. The proportion of PLHIVs that were married and living with spouse was 36.3%. A bigger proportion of men (46.5%), than women (30.1%), were married and living with spouse. The PLHIV population that was either divorced or separated accounted for 16.8% of the respondents, while 24.9% of PLHIVs were widowed. Larger proportion of women living with HIV (21.6%) than men living with HIV (9.6%) were single. Some 11.3% of men were in polygamous marriage.

### Forms of stigma and discrimination against PLHIV

**Non-invasive contact:** The community tended to keep off PLHIVs and to avoid physical contact, both with PLHIVs and those close to them. At least 56.0% of the PLHIVs had experienced each of the various manifestations of stigma in relation to non-invasive contacts with PLHIVs. Female PLHIVs experienced non-invasive contact related stigma, more than the male PLHIVs at an average score of 62.6 % against 57.0 %. Noninvasive stigma was highest among the married couples living with spouses, with an unweighted mean of 62.4 % and a weighted mean of 51.8 %. From the survey, 52.3 % of the PLHIVs indicated that some people would refuse to buy food from them in a market place if they were exhibiting signs of HIV. In schools, parents withdrew their children from schools where the children interacted with children from PLHIV households. According to some 51.5% of surveyed PLHIVs, some parents do not think it is safe to have their children play with HIV positive children in school.

**Shame, Blame and Judgement:** Shame, blame and judgement against PLHIVs were experienced both at the household and at the community levels. Women were however noted to receive more blame than men. From the survey, 77.9 % of the PLHIVs agreed that the community considered HIV a punishment from God and 61.9 % agreed that some people thought HIV is a punishment for bad behavior. Some 57.9 % had heard community discuss PLHIV as promiscuous people. Findings from the focus group discussions indicated that the community regarded PLHIVs as immoral people who were under punishment by Allah. Associating with PLHIVs was seen as getting closer to evil and therefore subjecting oneself to the possibility of encountering the same wrath from Allah.

**Enacted Stigma:** From the survey, 42.7% of the PLHIVs had at least once been abandoned by their spouses and 56.0% isolated in their households. About 47.5 % had been once or more times abandoned by family or sent away from the village; 34.5 % could not be touched by their spouses after they tested positive or after disclosing their status; 45.7 % had their partners leave after they tested positive or after disclosing their HIV status. Some 59.2 % felt they were no longer visited or less visited by family and friends, after they tested positive for HIV.

Violence against PLHIV was manifested both at the family/ household level, with PLHIVs thrown out of their residence, disinherited of their property and denied access to family resources. At least 58.5% of the PLHIVs had either been teased or sworn at and 51.1 % had at least once been treated with violence. Violation of PLHIV rights was common, with 28.3 % of the survey respondents indicating they had their property taken away, while 30.7 % had at least once been denied religious rites/services, and 25.5% had been physically assaulted. Gossip about PLHIVs was not uncommon, with 70.5 % of PLHIVs having encountered gossip in the community. Some 47.3% of the PLHIVs had either lost customers to buy produce/goods or lost a job, and 34.8 % had been denied promotion or further training due to their HIV status. From the group discussions, both with PLHIVs and with the general population, it

emerged that PLHIVs were not often allowed to rent office spaces or residential places. According to the survey results, 57.3 % of the PLHIVs had either lost housing or had not been able to rent housing as a result of their HIV status.

Findings from the interviews with the PLHIVs and from the discussions with the general population indicated that the PLHIVs were denied leadership opportunities in the community. The community perceived PLHIVs as people without moral standing and therefore did not deserve leadership positions. The community also considered PLHIVs as people who would use their leadership positions to infect others with the virus and provide opportunities for other PLHIVs to transmit the virus in the community. Self-stigma among PLHIVs also played part in their exclusion from leadership positions, with many opting not to seek such positions as a result of stigma. About 55.9% of the PLHIVs had been excluded from social gatherings, as a result of their HIV status, and 61.7 % lost respect within the family and/or community

Stigma and discrimination at the service delivery point: Stigma and discrimination against PLHIVs at the service delivery point was mainly in the form of non-consensual disclosure of HIV status, by a healthcare worker to a third party; denial of services; and provision of poor quality services. From the survey, 37.6 % of the PLHIVs had been given poor quality health services, at least once, as a result of their HIV status, while 36.4 % had at least once been delayed to receive healthcare services or received inferior care. From the focus group discussions, clients requiring surgical procedures were turned down once they tested positive for HIV. Pregnant women who tested HIV positive were also denied delivery support by healthcare workers. In some instances, the healthcare workers not only declined to provide the necessary services but as well did not disclose to the clients their HIV statuses. PLHIVs felt unwelcome as a result of provider attitude, specifically in regard to poor provider- client interactions, once their HIV positive statuses were known by the healthcare workers. In regard to nonconsensual disclosure of HIV status by a healthcare worker, the HIV status of 24.8 % of the PLHIVs had been disclosed by a healthcare worker without their consent. This kind of disclosure was experienced more by PLHIVs in Puntland (37.9 %) than in Somaliland (22.5 %) and SCS (23.0 %).

Self-stigma was enacted by the PLHIVs. Many PLHIVs lived in denial, mainly due to spiritual perspectives on HIV/AIDS, and due to HIV knowledge and awareness gaps. PLHIVs avoided seeking services at the ART Centers where they could be identified and made efforts to hide their identities, instead opting not to use their real names when registering for services at the ART Centers, while others used face masks to hide their identities.

### **Factors that perpetuate or mitigate stigma associated with HIV/AIDS.**

**Myths and misconceptions about HIV:** Stigma & discrimination is as a result of two main factors of myths and misconceptions manifested in the Somali community, and that include: 1) PLHIVs are evil persons and people do not want to associate with evil; 2) HIV is a death sentence that can be passed on to others who come into contact with PLHIVs and should therefore be avoided at full length. As a result of the myths & misconceptions about HIV, some PLHIVs stopped medication to seek alternative healing through traditional medicine and prayers for spiritual healing. Myths and misconceptions were escalated by the low levels of knowledge on the medical perspectives of HIV, especially in regard to its transmission and treatment.

**Inappropriate HIV/AIDS prevention messages:** Inappropriate prevention messages have been cited to further escalate stigma and discrimination against PLHIVs, especially due to the fact that the messages were perceived to invoke fear and prejudice. Messaging by the religious leaders, for example revolved around the association of PLHIVs with evil, mainly encouraging the community to avoid premarital and extramarital sex as the only modes of HIV transmission. The PLHIVs were therefore judged as those who had engaged in either of the two 'vices'. According to the PLHIV discussants, the messages conveyed in some IEC materials created an impression that HIV and death were almost synonymous.

**Unpreparedness of the health human resource work force:** Quality of service provision, specifically in regard to preparedness of the healthcare workforce to provide client friendly services to PLHIVs had not been emphasized in Somali. Some service providers felt that healthcare workforce had not received adequate training on handling PLHIVs without the risk of contracting HIV. Others thought there wasn't adequate equipment for protecting them against infection. In other instances, there was the perception that the stigma perpetrated by the healthcare workers was simply attitudinal issues that required training of the work force on client relations. In general, there was convergence in the opinion of the stakeholders, that the healthcare workers perpetuated stigma and discrimination against PLHIVs.

**Inadequate distribution of care and support services provided through the ART Centers:** While ART Centers mainly serve as access points for care and treatment of PLHIVs, the Centers also served as a source of information for the general public. The presence of the ART Centers also signified that there is a medical dimension to HIV, hence demystifying some of the community perceptions about HIV as a purely an issue of religion i.e. a curse from Allah. These Centers were however noted to be limited in number and in distribution across regions. As a result, communities in remote settings were less likely to interact with these facilities and by extension therefore were not in a position to encounter the medical perspectives of HIV treatment.

**Inadequate involvement of PLHIVs in planning and decision making:** AIDS commissions are the coordinating institutions for HIV program response in SCS, Puntland and Somaliland. To some extent, the Commissions have worked closely with PLHIVs through the existing PLHIV Networks. Participation and involvement of PLHIV at the community level and in the national response has been through establishment of organized groups in SCS, Puntland and Somaliland, attending planning and review meetings organized by the AIDS Commission. The contribution by PLHIV and civil society in general to decision making was however limited by their inadequate capacity to engage.

**Low PLHIV Network activities:** Two networks had been established, South Central Somalia PLHIV Network in the SCS, and Talowadag in Somaliland while none had been established in Puntland. The PLHIV Networks have demonstrated significant response in addressing the plight of PLHIVs, working closely with the Integrated Comprehensive Care and Support Centers (IPTCS), Government Ministries, NGOs and CBOs. The PLHIV Networks played great roles in responding to the plight of the Network members. These roles included: providing alternative accommodation/ residence for PLHIVs sent away from their homes; provision of transport for those relocating as a result of stigma and discrimination, burial support for PLHIVs neglected by families; delivery of ARVs to network members in the rural/ remote settings; special delivery of ARVs to government officials and religious leaders who did not want to be associated with the Centers; payment of school fee for children from PLHIV households; psychosocial support for PLHIVs; occasional procurement of drugs for OIs for members, when such drugs lacked in the health service outlets; referrals and linkages of PLHIVs with services.

The Networks provided an institutional platform through which the PLHIVs could engage with the relevant government agencies. Representatives of the networks engaged with the government departments in the ongoing discussions regarding HIV policies, legal and institutional environment. The networks also worked closely with development partners in designing and implementing HIV/AIDS related programs, while advocating for stakeholder responses to the plight of PLHIVs.

While the progress made by the PLHIV Networks, where the Networks exist, remains impressive, a number of gaps still limited their potential in responding to the needs of PLHIVs. The scope of activities implemented by the Networks were limited by low financial and human resource capacities of the Networks. There was limited capacity to implement relevant programs, and to attract and absorb funds for implementation of programs. The absence of a PLHIV Network in Puntland was a glaring gap that made the region lag behind in championing PLHIV needs.

**Inadequate policy, legal and institutional infrastructure for PLHIV Rights:** Violation of PLHIV rights was escalated by weak policy, legal and institutional mechanisms to address the rights of PLHIVs. Both SCS and Puntland had draft HIV policies that were due for ratification and approval, a process that had been slow paced. In Somaliland, the HIV policy in place was developed in 1999. There were plans to review the policy considering that transformations had taken place over the 16 years period since the implementation of the policy started. In all cases, there were draft HIV bills that were due for enactment in parliament. The fact that some HIV policies had not been ratified and the fact that the HIV bills had not been enacted are indicative of the unprepared legal and regulatory environment. As a result of weak HIV policy, legal frameworks, the PLHIVs were unable to access justice in instances where their rights have been violated.

**Weak post HCT linkages with care and treatment:** Weak post HCT linkages of PLHIVs with care and treatment services as a result of unstructured referral systems was noted as a barrier to Service access and utilization. As a result of these gaps in referrals and linkages, many people who tested positive for HIV did not receive timely psychosocial support and succumbed to self-stigma. Transition management, post HCT remains a key priority area that needs to be emphasized in HIV response.

## Effects of stigma and discrimination on HIV prevention, treatment care and support services

**Stigma leads to low uptake of HCT:** Low HCT uptake was as a result of myths and misconceptions associated with HIV, especially in regard to the association of HIV infection with religion. The perception that HIV infection did not have any medical relevance, and that it was an evil disease, prevented many people from seeking HIV testing services.

**Stigma leads to non-disclosure or delayed disclosure of HIV Status:** As a result of HIV related Stigma and discrimination, many PLHIVs did not disclose their HIV status. From the survey, 71.3 % of the respondents were worried that those who knew their HIV status would disclose that to others. Female PLHIVs were more worried about third party disclosure than were the male PLHIVs (73.7 %; 67.4 %). Overall, 90.1 % of the respondents were careful to whom they disclosed their status (Female: 91.5 %; Male: 87.9 %). On the other hand, 87.3% of the PLHIVs thought that, telling someone that they are HIV positive was something very risky (Male: 84.0 %; Female: 89.3 %). Nearly all the PLHIVs made a big effort to make sure that their HIV status is kept a secret (92.8 %). Again, female PLHIVs were more likely to make a big effort in keeping their HIV status secret (94.4 %) than were the male PLHIVs (90.1 %).

About 15.2 % of the PLHIVs had not disclosed their HIV status to anyone. The proportion of PLHIVs disclosing their status within six months was lower in Puntland (49.5 %) than in Somaliland (62.4 %) and SCS (69.6 %). In addition, a bigger proportion of PLHIVs in Puntland (18.4 %) had never disclosed their HIV status to anyone, compared to Somaliland (14.6 %) and SCS (14.3 %). Majority of those who had disclosed their HIV status to a third party in Puntland had only done so to a healthcare provider (31.1 %). However, Puntland had the highest proportion of those who had disclosed their HIV status to their spouses (26.2 %) compared to Somaliland (20.6 %) and SCS (18.7 %).

**Stigma leads to loss of family and friends (Social exclusion):** From the survey, 85.9 % of the PLHIVs reported that PLHIVs lost love and guidance in the family, and 90.3 % reported that they became lonely as a result of stigma and discrimination. Another 89.3 % reported that HIV stigma and discrimination led to weakened family bonds. A larger proportion of female PLHIVs than male PLHIVs (Male (63.1 %); Female (68.6 %)) indicated that PLHIVs wished they had not married. Overall, 66.5 % of the respondents reported that the PLHIVs wished they had not married.

**Stigma leads to high service seeking costs and non- adherence to ART treatment:** HIV related stigma led to escalated service seeking costs, mainly associated with long distance traveled to seek medication. From the survey, 77.9 % of the respondents reported that PLHIVs spend a lot of money on transport to access treatment far away from their locality, as a result of HIV related stigma (Male: 80.9 %; Female: 76.1 %). The implication is that those who feared they would be identified at the local ART Centers but who did not have money for transport would at times fail to get medication in time or fail to continue with medication, altogether. This was also echoed by 79.3 % of the PLHIVs who reported that stigma affects adherence to medicines. On the other hand, denial led to many PLHIVs not initiating medication and others stopping treatment. The effect of denial includes delayed medication and access to social support services.

**Stigma causes depression and sometimes suicidal ideation:** Both denial and non-disclosure led to depression and in some cases suicide. According to 75.9 % of the PLHIVs, stigma had led to high death rates in the community. This view was shared by 73.0 % of the male PLHIVs and 77.6 % of the female PLHIVs. Another 81.2 % reported that PLHIVs die early as a result of stigma related stress, while 77.5 % reported that stigma could lead to suicide among PLHIVs. Early death of PLHIVs came with an increase in the number of OVCs, with 76.1 % of the PLHIVs owning that stigma led to increase in the number of OVCs.

**Stigma leads to vengeance and more HIV infection:** As a result of HIV stigma in the community, some PLHIVs engaged in unprotected sex with the intention of infecting others. From the survey, 84.9 % of the PLHIVs reported that stigma leads to high rate of HIV infection. According to 76.7 % of the respondents, PLHIVs who are stigmatized may turn violent and indulge in vengeance.

**Stigma leads to loss of skilled and non-skilled work force in the community:** Discrimination against PLHIVs led to loss of both skilled and non-skilled human resources in the community. From the survey, 77.9 % of the PLHIVs, 80.9 % of male PLHIVs and 76.1 % of the female PLHIVs shared the view that stigma had led to increased work load in the community. Some 75.6 % of the PLHIVs (Male: 77.3 % and Female: 74.6 %) thought that the community had lost advisors as a result of stigma.

**Stigma leads to loss of access to livelihoods for PLHIV and their households:** Workplace related HIV stigma and discrimination was cited across all the group discussions and in the key informant interviews as one of the factors that led to loss of access to livelihoods among PLHIVs.

### **Quantitative stigma and discrimination index (SDI)**

**Overall Stigma Index:** The scores for each category was computed using individual variable responses under each category and provided the following values: non-invasive stigma (10.0); reservations on HIV/ AIDS disclosure (17.0); Shame blame and judgment (11.8); enacted stigma (7.0); experience of cumulative stigma effect (16.0). The overall stigma index was hence estimated at 61.8

**Comparison of Stigma Index across the SCS, Somaliland and Puntland:** Somaliland had the highest stigma index rating of 65.0. Puntland and SCS had a similar rating of 55.5 each. According to some stakeholders, one would expect lower stigma levels in SCS and Somaliland than in Puntland, as a result of the established PLHIV Networks. On the other hand, some stakeholders also opined that the PLHIV Networks had not scaled up activities to a level that can effect a significant change. The high HIV Stigma for Somaliland may be as a result of the high level of interactions in the region. According to the interviewed stakeholders, families/ households in Somaliland are closely knit and the community members well known to each other, compared to Puntland and SCS where interactions between families and households are not as common. The possibility of PLHIVs experiencing stigma and discrimination is higher when they interact more often with other members of the community, than in instances where their interactions are limited.

**Comparison of stigma index across gender:** The stigma index for the female PLHIVs was higher than that of the male PLHIVs. The indices were 63.0 and 60.6 for female and male PLHIVs respectively. The female PLHIVs had higher index than the male PLHIVs in each of the 5 categories of analysis. This variation was attributed to the fact that women were more often than not, the first to undergo HCT, when they visited health facilities for services such as ANC. As a result, the women were perceived to be the first partner in a relationship to be infected and were therefore blamed by the spouse/ partner and the community. The socio-cultural position of women in the community also played a role in escalating stigma against women. The roles of women in the community implied that they were more likely than the men to be exposed to stigma.

### **Conclusions**

Stigma and discrimination against PLHIVs is very high in Somali, both in terms of self-stigma among PLHIVs and in terms of stigma manifested by the general community against PLHIVs. The main factors behind high levels of stigma include low levels of HIV knowledge and awareness in the community, creating room for myths and misconceptions to thrive in the community. Knowledge and awareness gaps are further confounded by the religious perspectives in regard to HIV transmission and treatment. While efforts have been made at various levels, to address HIV knowledge gaps, results are yet to be realized. Community reach has been low due to inadequate distribution of activities implemented by CSOs, PLHIV Networks and other stakeholders involved in HIV work. In addition, HIV resources were low and the stakeholders did not have the adequate financial and human resources to implement HIV knowledge and awareness programs. While HIV messaging has undergone a lot of transformations worldwide, the prevention messages in Somali still tend to scare the community, rather than provide information that stimulates behavior change without necessarily propagating stigma.

The manifestation of stigma and discrimination against PLHIVs, by the healthcare workers is inhuman and violates the rights of the PLHIVs. Weak human resource capacity, including gaps in client relations and low capacity to provide services without fear of contracting HIV, are the major contributors to this kind of stigma.

The policy environment was not supportive of PLHIV needs. Although there were ongoing initiatives to strengthen the policy environment, pace of these ongoing processes remained low and needed to be fast tracked so that the policies are brought to force. Weak legal and institutional frameworks for enforcement of PLHIV rights is a major enhancer of stigma and discrimination in the republic. Like in the case of policies, the draft bills that exist need to be enacted and relevant institutions strengthened to support their implementation.

The PLHIV Networks have a high potential for fighting stigma and discrimination through engagement with PLHIVs and with the general community. The Networks also have great potential in engaging in the policy processes, program

planning and decision making at the National and Sub National levels. They did not however realize their full potential due to their low capacities, limited presence and inadequate resources.

### **Recommendations**

- I. Support the review and harmonization of HIV prevention and treatment messages, and the development of more relevant and effective messages. Addressing medical perspectives of HIV transmission and treatment may be integrated under sexual and reproductive health messaging in order to gain greater acceptance by the community.
- II. Provide capacity building support to the healthcare workforce, including training on client friendly services and provision of the necessary protective equipment that prevents the risks of healthcare worker contracting HIV during service provision. It will also be important to provide training on universal precautions for infection prevention to enable the healthcare workers deliver services without fear of contracting HIV.
- III. Strengthen post HCT linkages with care and support. This will help minimize the number of PLHIVs succumbing to denial and self-stigma, by ensuring that the persons testing positive for HIV are linked to the necessary psychosocial support, care and treatment. Strengthening such linkages may require establishment of post HCT support groups and strengthening referral systems among others.
- IV. Strengthen advocacy against HIV Stigma and discrimination. The advocacy approach should be innovative and should target key audiences with relevant messages. The campaigns should for example target religious leaders as key influencers of religious perspectives of HIV. Anti-stigma campaign activities should also work with the religious leaders as ambassadors of change. Also to be targeted should be the key government officers who are PLHIVs and who may engage as champions against PLHIV stigma and discrimination. The approach should promote magnification of champions within PLHIV communities as role models to address self-stigma issues and show that PLHIVs too can have their rights respected, live with dignity and productive life.
- V. Strengthen PLHIV Networks by building the capacity of the existing Networks and supporting the establishment of a PLHIV Network in Puntland. Capacity strengthening for the Networks should aim at empowering their internal capacity to mobilize and attract resources for HIV programming; expanding their capacities to better coordinate PLHIV activities at the National and Sub National Levels as well as their ability to decentralize their activities for greater reach at the community. This way, the Networks will be able to engage with other CSOs operating at different level and expand access to care and support services to its members. The terms of reference for the Networks should clearly define their expected roles and the capacity required to perform such roles, so that the capacity building initiatives are tailored to evident needs.
- VI. Finalize the ongoing policy processes. The relevant government departments should prioritize and fast track the ongoing policy processes. PLHIVs, through their Networks and while working with other stakeholders, should advocate for quick finalization and adoption of the policies. Once finalized, the policies should be disseminated and relevant stakeholders sensitized. Implementation capacities of the relevant stakeholders should also be strengthened to facilitate the implementation of the policies. The PLHIV networks should be supported to monitor the implementation of these policies.
- VII. Strengthen the legal and institutional frameworks for enforcement of PLHIV rights. This should include enactment of the pending HIV bills, followed by sensitization of stakeholders including the PLHIVs and the general community. The relevant institutions expected to enforce the PLHIV rights should be empowered to implement the acts.

## **I. Introduction**

### **I.1 Background**

World leaders in the UN high level meeting in 2001 committed to achieving universal access to HIV prevention, care, support and treatment. This was again reaffirmed during the high level meeting in June 2011. The Global leaders recognized that full realization of all human rights and fundamental freedoms for all is an essential element in the global response to the HIV epidemic, including in the areas of prevention, treatment, care and support. The leaders also recognized that addressing stigma and discrimination against people living with, presumed to be living with or affected by HIV, including their families, is also a critical element in combating the global HIV epidemic.

UNICEF (2007) defines HIV-related stigma as a process of devaluation of people living with or associated with HIV/AIDS. Stigma can be projected by other people or can be “felt” or “self-stigmatization”, and termed ‘internal stigma’. A person who is stigmatized is seen as having less value or worth to other people (International Planned Parenthood Federation (IPPF, 2008). Discrimination involves treating someone in a different, unjust, unfair or prejudicial way, often on the basis of their actual or perceived belonging to a particular group. It consists of actions or omissions that are a result of stigma and directed towards the individuals who are stigmatized. Discrimination is ‘enacted stigma’ (IPPF, 2008; UNICEF, 2005).

HIV-related stigma and discrimination are more increasingly recognised as a huge barrier to combating AIDS in sub-Saharan Africa and elsewhere. Stigma and discrimination are a health and human rights issue. They pose obstacles to achieving universal access to prevention, treatment, care and support. Stigma and discrimination are associated with lower uptake of preventive services, testing and counselling; reduced and delayed disclosure of HIV sero-status; and postponing or rejecting care, seeking healthcare services outside one’s community for fear of breach of confidentiality. Stigma and discrimination affect more severely women and girls, and vulnerable populations such as sex workers, widows, prisoners and TB patients (Ogden and Nyblade, 2005; UNICEF, 2007).

International civil society and organisations such as 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/AIDS (UNICEF) have spearheaded global initiatives to measure stigma and discrimination. They support countries through means such as advocacy, strategic planning, capacity building, and resource mobilisation to address stigma and discrimination faced by people living with HIV (PLHIV). SCS is one of the countries that participated in these pilot studies.

The Greater Involvement of People Living with HIV/AIDS (GIPA) is a principle that was first advocated in 1983 by PLHIV in Denver, formalised at the 1994 Paris AIDS summit and endorsed in 2001 by the United Nations General Assembly. GIPA aims to realise the rights and responsibilities of people living with HIV and enhance the quality and effectiveness of the AIDS response. The rationale is that through the involvement of individuals and communities vulnerable to, and infected by HIV, will improve the relevance, acceptability and effectiveness of programmes.

### **I.2 Magnitude of HIV/ AIDS in Somali**

HIV prevalence in Somali is relatively low, compared to her neighbors. At the end of 2013, it was estimated that approximately 31,000 adults and children were living with HIV and AIDS in SCS of whom 51% were women and 49% were men. According to a report by UNAIDS, the number of PLHIVs for Somali was

estimated at 35,000 in 2014, with an adult prevalence rate of 0.55% and an annual number of new infections stabilizing at 3,200 over a period of about 5 years. ANC surveillance in 2014 identified a median HIV prevalence rate of 0.71%, 0.53% and 0% in Somaliland, Puntland and SCS respectively. The number of adult new infections were estimated at 1,434 for SCS (or 0.04% incidence rate); Somaliland at 980 (or 0.1% incidence rate); Puntland at 278 (or 0.06% incidence rate).

While Somali is currently experiencing a low prevalence of HIV epidemic, results of Integrated Bio Behavioral Surveillance (IBBS) Surveys conducted in 2008 and 2014 in Hargeisa have shown that HIV prevalence among Female Sex Workers (FSWs) is ten times higher (5.0%) than that among Antenatal Care (ANC) attendees (0.5%). Moreover, three main towns of Mogadishu, Bossaso and Hargeisa have the highest HIV prevalence. Two main modes of HIV transmission have been identified to include Mother to Child Transmission (MTCT) and heterosexual transmission. According to the National Strategic Plan for HIV 2015- 2020, heterosexual transmission accounts for the majority of transmission of HIV in SCS, Puntland and Somaliland. From the same strategy, perinatal transmission of HIV comes second after heterosexual transmission. Mother to child transmission (MTCT) rate was estimated at 47% in 2014. The high MTCT rate has been attributed to low uptake of PMTCT services with only 2.5% of eligible mothers receiving ARVs for PMTCT in 2014.

Efforts to address HIV in Somali have been frustrated by the high implementation costs, in a context with limited resources. HIV/ AIDS response in Somali is almost entirely dependent on the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM). Government expenditures on HIV/ AIDS is mainly in form of health facility infrastructure, specifically in staff salaries and physical infrastructure at the general health service delivery outlets. Other financial resources by the government were allocated to the AIDS Commissions, mainly to support operational activities. As a result of the limited financial resources and other factors, there is minimal access to healthcare, a scenario that has been further complicated by inequitable distribution of healthcare resources in favour of the urban population. The rate of access of health services by the urban population is estimated at 50% against 15% for the rural population.

### **I.3 HIV/AIDS Stigma in Somali**

In Somali, the level of stigma is presumed to be very high, and likely to prevent people living with HIV from coming out openly to seek health services. According to the MICS4 of 2011 in the Northeast and Northwest Zones, only about 1 in 10 people expressed accepting attitude towards people living with HIV when asked a series of four questions on attitude towards people living with HIV. Indeed one third believe that a female teacher living with HIV should be allowed to teach their children, another one third would not buy fresh vegetables from a shop keeper living with the virus. This being the view of the general population, is indicative of the high level of stigma towards people living with HIV. There has however been no large scale Stigma and Discrimination study, undertaken in Somali.

### **I.3 Objectives of the Study**

The overall objective of this study was to generate strategic information on HIV related stigma and discrimination to guide interventions that address HIV related stigma and discrimination and policy frameworks. The results from the study are expected to provide a powerful advocacy tool to address HIV related stigma and discrimination.

#### **Specific Objectives**

1. To study and document the levels of various forms of HIV-related stigma and discrimination against PLHIV, focussing on the individual, family and community levels.
2. To identify and document factors and manifestations that perpetuates or mitigate stigma associated with HIV and AIDS.
3. To document the effects of stigma & discrimination on HIV prevention, treatment care and support services
4. To compute a quantitative stigma and discrimination index for the study area
5. To draw conclusions from the study and make recommendations to support advocacy program, policies that will enhance the quality life for people living with HIV.

## 2. Study Methodology

### 2.1 Study Design

The study was a cross-sectional survey using mainly quantitative methods. The quantitative survey approaches sought to measure the overall stigma index and stigma indices for diverse forms of stigma. Qualitative approaches were also used to explore the various forms of stigma by population segments and by region. The study was conducted in South Central Somali (SCS), Puntland and Somaliland. Proportionate samples were derived from each of the areas.

### 2.2 Study Population and Sampling

All respondents in the quantitative survey were sixteen years old and above and who received HIV care and treatment at registered ART Centers. The ART Centers were selected randomly for inclusion in the study. However, for cost and logistics considerations, and where certain ART Centers had low number of clients, priority was given to high volume ART Centers. All the clients, both pre ART and those already on ART were eligible for participation in the study. Further eligibility criteria included client stability and for ethical reasons, those who were not in stable condition were not included in the study. Table I shows the distribution of the quantitative sample population across the ART Centers.

**Table I: Quantitative Study Sample**

<b>Focus Area/ ART Client Population</b>	<b>ART Center</b>	<b>PLHIV Population</b>	<b>Sample Size</b>
<b>Somaliland</b> 1,411 ART Clients	Borama Hospital	197	73
	Berbera Hospital	143	50
	Hargeisa Hospital	857	294
	<b>Total</b>		<b>417</b>
<b>SCS</b> 737 ART Clients	Benadir	455	146
	Mercy USA	127	46
	Merka	114	38
	<b>Total</b>		<b>230</b>
<b>Puntland</b> 365 ART Clients	Bosasso Hospital	116	56
	Garowe Hospital	93	47
	<b>Total</b>		<b>103</b>
<b>Total</b>			<b>750</b>

Qualitative data collection methods included Key Informant Interviews (KII) and Focus Group Discussions (FGDs) and targeted the general population, PLHIVs, and stakeholders from the Civil Society Sector, MOH Management Teams, PLHIV Networks, Health Service Providers at the ART Center and in the Non- ART Health Facilities and AIDS Commissions. The Social Workers and Healthcare Workers supported the identification of members of the general population that met the criterion for inclusion in the study. The Government Officers, CSO Representatives, Service Providers and the PLHIV Network' Officials were selected using snowballing technique. PLHIVs were selected from the ART Centers. The selected PLHIVs were those that had not been sampled for the quantitative component of the study.

### 2.3 Data collection

All the field data collection teams were Somali speaking and comprised of enumerators, supervisors and focus group discussion facilitators. The enumerators were distributed across the ART Centers based on the sample size in each Center. A target of 5 interviews was set for each enumerator. It was assumed that this would optimize quality data collection process, allowing for time to review and verify the data together

with the supervisors at the end of each day. One supervisor was attached to each of the ART Centers. On the other hand, two FGD facilitators, one as a moderator and another as a note taker, were assigned each to Puntland, Somaliland and SCS. Prior to dispatch to the field, all the data collectors and the supervisors underwent three days intensive training. The training covered basic research skills and HIV/AIDS Stigma. The trainings also provided an opportunity for the data collectors to understand the protocol for study implementation and to acquaint themselves with the study tools.

The enumerators conducted alternate mock interviews among themselves (interviewer on one hand and interviewees on another) and provided insightful feedback on their experience with the tool. After the mock interviews, the respondents were asked what they thought about the tools and their contact with interviewees. Similarly the returning teams were asked whether they felt sufficiently equipped to carry out the survey or if they encountered any challenges administering the tool. The aim of the mock interviews was to assess the workability of the tools, ensuring that the information is easy to follow and that questions are clearly coded. The field supervisors certified the proper interpretation (or not) of the meaning of the questions asked and verified that the same concepts were maintained. Comprehension difficulties were noted and the need to clarify any questions and answers, or to review a translation of the questionnaire, to check that the answers truly matched the local conditions, were all noted and acted upon as appropriate. This was particularly helpful in Somaliland where the trainees noted disparities in the dialects used in the tools and the dialect of the Somaliland Community.

## **2.4 Study Tools**

The quantitative study instrument included questions on respondents' background characteristics; knowledge; use of HIV/ AIDS drugs; marriage & live-in partnerships. The scope of the tool also covered the lived experiences of PLHIV on aspects of stigma and discrimination in broader domains of access to care and treatment services, employment, reproductive rights and effecting change. Questions were asked verbatim and rephrased only if a respondent did not understand. Retrospective experiences were limited to the previous one year before the survey on the assumption that the 1 year period was representative of the current situation and was adequate enough to prevent recall biases.

Qualitative data tools included semi structured FGD guides and KII guides that were open ended and allowed for probes by research teams to explore details on emerging themes as identified during the data collection exercise. Both the qualitative and quantitative study tools were finalized with input from UNICEF and partners, and were translated into Somali language.

## **2.5 Confidentiality of Participant Information**

The research teams were trained on the need for confidentiality. Interviewers were made aware of the importance of minimizing anxiety or stress and of the absolute requirement of not divulging any information received from study participants. Data collector training included focused discussions and exercises regarding the meaning and process of informed consent and the importance of protecting the privacy of the participants and confidentiality of the information obtained from them.

All collected data was treated with confidentiality. No names of study participants appeared on any tool used to capture information. The data forms were only accessible to the members of the research team. No identifying information has been disclosed in this report, and any presentations or publications that will be derived from this study will not disclose such information.

## **2.6 Informed Consent**

Written informed consent to participate in the study was obtained from all the study participants prior to enrollment in the study. Before commencement of any interview, interviewers read the information on the consent forms to the respondents, providing detailed information including the risks and benefits associated with participation in the study. Only the participants who understood and accepted the information provided in the consent form were eligible for participation.

## **2.7 Ethical Clearance**

The study sought and obtained approval from the government authorities in SCS, Puntland and Somaliland prior to the survey. In each case, the comments provided by the relevant Authorities were integrated into the protocol prior to its implementation.

## **2.8 Limitations of the Study**

From the existing literature and from the findings of this study, there was consensus that a large proportion of people infected with HIV/ AIDS may not have been diagnosed and hence not aware of their serious status. This opinion was attributed to the low HCT uptake across the entire Somali. As a result of stigma, a number of PLHIVs live in denial and hence do not seek care and treatment services. The sample was drawn entirely from the clients receiving services at the ART Centers. To some extent therefore, the sample may not have provided accurate representation of the PLHIVs in Somali.

Pilot testing of the tool was not undertaken and mock interviews were used instead. As a result, the researchers did not have an opportunity of testing the tool in a population similar to the study population hence limiting the refinement of the tool. A few variables were therefore not well captured during the data collection. These included the variables on income and those that captured information on commercial sex work/ relationships with commercial sex workers.

### 3. Findings and Discussions

#### 3.0 Socio-demographic characteristics of the sample population

The mean age of the study participants, in years, was 38.8, with a minimum of 16 and maximum of 80. The standard deviation of age was 10.11 and the variance was recorded at 102.2. Majority of the respondents were aged 35-49 (48.7%). Other age Categories represented in the study included: 16-24 (6.1%); 25-29 (14.0%); 30-34 (16.0%); >=50 years (15.2%).

The respondents included 62.4% (468/750) female population and 37.6% (282/750) males. Against 59.7% (448/750) of the respondents who had not attended school, 38.4% (288/750) reported they had attended school. Of the 288 respondents who had attended school, 63.9% (184/ 288) had primary level of education, 27.1% (78/288) had secondary level education and 5.2% (15/ 288) had higher levels of education. The minimum number of education years was recorded at 1 year, with a maximum of 20 years, a range of 19 and a mean of 7.4 years, 3.634 standard deviation and 13.205 variance.

Majority of the respondents were either not working (60.3%) or self-employed (20.4%), while only 15.6% were in salaried employment. Almost all the Respondents had been in marriage at one point in their lives (96.0%; (720/750)) against 4% (30/750) who had never been married. The mean age of marriage for the male population was 23.5 years while that of female was 18.1 years. Table 2 provides the details on age at first marriage.

**Table 2: Age at First Marriage**

	Minimum	Maximum	Mean	Standard Deviation
Overall	11	45	19.86	5.320
Male	11	45	23.05	6.006
Female	13	40	18.21	4.046

The study estimated the proportion of PLHIVs that were married and living with spouse at 36.3%. A bigger proportion of men (46.5%), than women (30.1%), were married and living with spouses. The PLHIV population that was either divorced or separated accounted for 16.8% of the respondents, while 24.9% of PLHIVs were widowed. Larger proportion of women living with HIV (21.6%) than men living with HIV (9.6%) were single. Table 3 provides details on the marital status of the PLHIVs

**Table 3: Marital Status**

Status	Overall (%)	Male (%)	Female (%)
Currently married, living with spouse	36.3	46.5	30.1
Currently married, but separated	6.3	5.3	6.8
Divorced	10.5	12.4	9.4
Widowed	24.9	19.1	28.4
Single	17.1	9.6	21.6

Some 11.3% of men reported they were in polygamous marriage. Of the men who provided information on their polygamous or monogamous marital relationship, 15.0% of those from Somaliland were in a polygamous relationship while the proportion for SCS and Puntland were 13.6% and 13.3% respectively. On the other hand, 24.1% of the women living with HIV reported that their husbands had other wives. Of the women who provided information on whether or not their husbands had other wives, 28.9% of

those from Somaliland indicated that their husbands had other wives while the proportion for SCS and Puntland were 14.4% and 22.9% respectively.

### 3.1 Forms of stigma and discrimination against PLHIV at individual, family and community levels

Stigma and discrimination, in Somali, like in other settings, manifests itself in various forms at the individual, family and community levels. Many tags were used to describe HIV in a manner that is stigmatizing. Some of the tags included: the lion; the killer; Tiger; thinning disease; the bad one; the three word disease. According to the general population, these names were chosen because the HIV/ AIDS disease is the worst of all diseases and once you are infected, the ultimate end is death. The various forms of stigma have been discussed below.

#### 3.1.1 Stigma associated with Noninvasive contact with PLHIVs

The community tended to keep off PLHIVs and to avoid physical contact, both with PLHIVs and those close to them. Findings from the focus group discussions with PLHIVs and with the general population

*“Honestly, I am scared from PLHIV. I am not willing to interact with or support them.”*  
(FGD Participant-  
General Population)

indicated that, people were not willing to share facilities with persons living with HIV. Cases were cited in which household utensils were discarded after such items were used by PLHIVs. For fear of acquiring HIV, individuals avoided shaking hands with PLHIVs.

The community was not free transacting business with PLHIVs. From the survey, 52.3 % of the PLHIVs indicated that some people would refuse to buy food from them in a market place if they were exhibiting signs of HIV. About the same proportion (53.5 %) shared the same thought in Somaliland, 42.6% in SCS and 68.9% in Puntland. According to the discussants, both in the general population and PLHIVs, there were cases of HIV stigma related job losses, both in the private and public sectors, including in some of the key government institutions. PLHIVs seeking employment were denied opportunities while PLHIVs in employment lost their jobs as a result of their HIV positive status.

Regarding sharing of communal resources, it emerged that the PLHIVs were not denied access to some of these resources, only due to the fact that the resources were not controlled by individuals but either by the private sector or by the government. The implication, as in the case of rental houses in which the PLHIVs were denied opportunity to rent, was that the PLHIVs would not be allowed to access some of these communal resources if they were under the custody of individuals within the community.

The community kept their children off PLHIVs and did not allow them to play with children from PLHIV

*“When a female PLHIV is known in the community, all her children are associated with the virus and the other children do not want to play together with such children while in school. They are isolated and stigmatized by their peers. Parents of the other children then begin to pull out their children from that school and transfer them to other schools.”*

households. In schools, parents withdrew their children from schools where the children interacted with children from PLHIV households. According to some 51.5% of surveyed PLHIVs, Some parents did not think it is safe to have their children play with HIV positive children in school.

From the survey, at least 56.0% of the PLHIVs had experienced each of the various manifestations of stigma in relation noninvasive contacts with PLHIVs. The average scores, overall, was 60.5% and for Somaliland (60.4%); SCS

(60.5%); Puntland (61.2%). As indicated in table 4, there were no variations between the three regions in regard to PLHIV experiences with stigma associated with noninvasive contact.

**Table 4: Non Invasive contact with PLHIVs**

Personal Experiences	Somali (%)	Somaliland (%)	SCS (%)	Puntland (%)
People not willing that I cook at functions	60.4	60.4	58.7	64.1
People not willing that I share meals at functions	64.4	63.6	64.8	66.0
People not willing that I serve guests meals	62.3	61.6	63.0	63.1
People not willing that I share beddings	59.2	60.9	57.4	56.3
People not willing that I share soaps	56.1	59.5	50.0	56.3
People not willing I shake hands	60.8	56.1	69.1	61.2
Average	60.5	60.4	60.5	61.2

Female PLHIVs experienced noninvasive contact related stigma, more than the male PLHIVs at an average score of 62.6 % against 57.0 %. To some extent, this variation may be attributed to the nature of questions that were asked under this category, in relation to the socio cultural dynamics of the Somali community. It will be noted for example, that the scores for female was much higher for 'People not willing that I cook at functions', with a score of 64.5% for female and 53.5 % for male. Gender roles may have influenced the responses under this category. To a great extent however, the variations were determined by other practices that cut across gender.

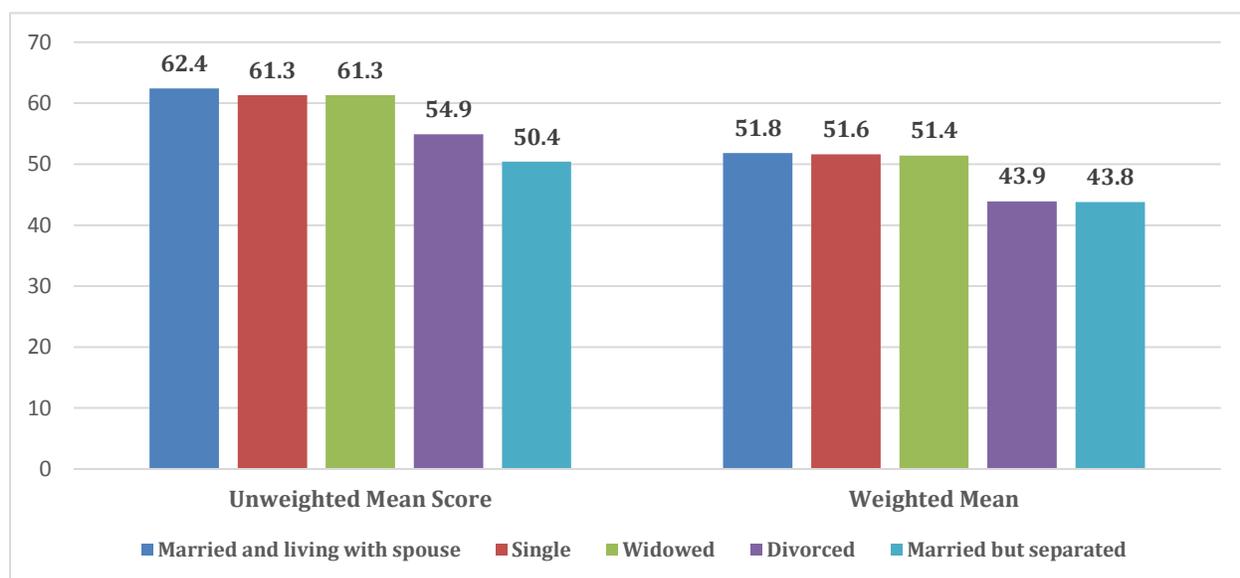
Experiences of Noninvasive contact related HIV stigma was not any much different for those who ever attended school (61.4) and those who never attended school (59.9). Table 5 shows the comparisons on experiences with noninvasive stigma across gender and comparisons based on school attendance.

**Table 5: Noninvasive contact with PLHIVs- Gender and Education**

	Female (%)	Male (%)	Never attended School (%)	Ever attended School (%)
People not willing that I cook at functions	64.5	53.5	59.6	60.4
People not willing that I share meals at functions	66.5	60.3	62.9	66.3
People not willing that I serve guests meals	65.6	56.7	62.5	62.2
People not willing that I share beddings	61.1	56.0	57.8	61.1
People not willing that I share soaps	59.0	51.4	56.3	55.9
People not willing I shake hands	58.8	64.2	60.5	62.2
Average	62.6	57.0	59.9	61.4

Noninvasive stigma was highest among the married couples living with spouses, with an unweighted mean of 62.4 % and a weighted mean of 51.8 %. There was however no major difference between the mean scores for this category of PLHIVs and the mean scores for single PLHIVs (weighted mean of 51.6 %); widowed PLHIVs (wighted mean of 51.4 %). PLHIVs who were married but separated experienced the lowest stigma, with a weighted mean score of 43.8%, followed closely by divorced PLHIVs with a weighted mean of 43.9%. From the FGDs, married PLHIVs who live with their spouses have a more interactive life, including with their children and other family members and are therefore likely to experience this form of stigma, unlike the divorced and separated spouses who are likely to have minimal interactions and that are likely to relocate and lead private lives in locations where they are not known and their HIV statuses not known. Figure 1 shows the variations in noninvasive stigma across the marital statuses.

**Figure 1: Noninvasive stigma vs. marital status**



### 3.1.2 Shame, Blame and Judgement

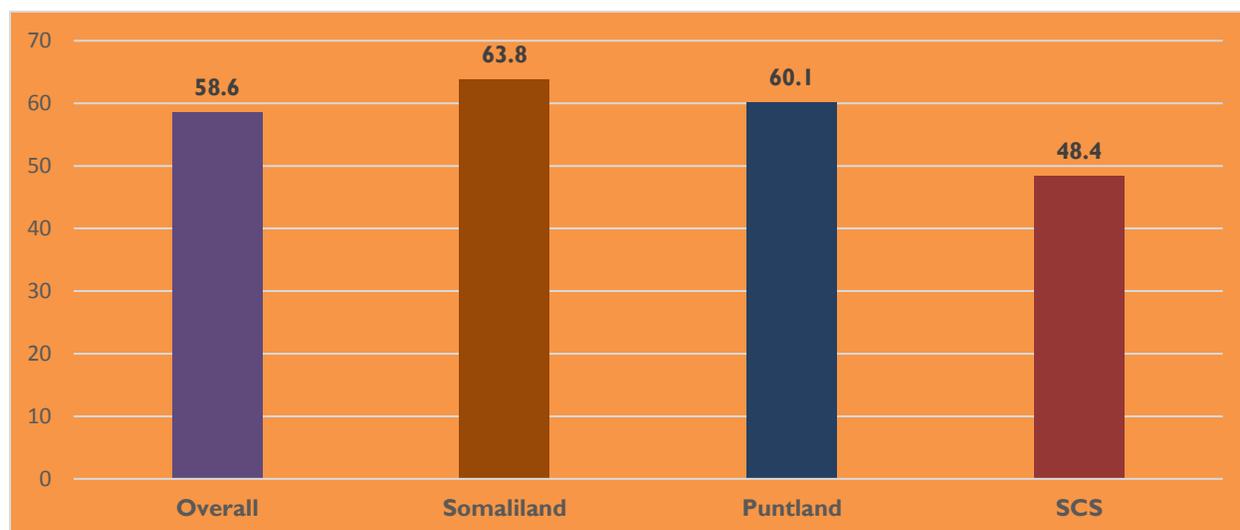
Shame, blame and judgement against PLHIVs were experienced both at the household and at the community levels. Women were however noted to receive more blame than men. From the survey, 77.9 % of the PLHIVs agreed that the community considered HIV a punishment from God and 61.9 % reported that some people thought HIV is a punishment for bad behavior. Some 57.9 % had heard community discuss PLHIV as promiscuous people. Table 6 shows the proportion of PLHIVs who had heard the community shame, blame and judge PLHIVs.

**Table 6: Shame, blame and judgement**

	Overall (%)	Somaliland (%)	SCS (%)	Puntland (%)	Male	Female
HIV is a punishment from God	77.9	81.5	79.6	59.2	78.4	77.6
Some people think HIV is a punishment for bad behaviour	61.9	68.6	48.7	64.1	60.3	62.8
Most people with AIDS deserve what they get	57.9	61.4	40.0	83.5	56.4	58.8
It is women prostitutes who spread HIV in community	65.3	74.1	54.3	54.4	68.8	63.2
People with HIV are promiscuous	51.5	57.3	38.7	56.3	51.1	51.7
People with HIV should be ashamed of themselves	66.1	67.1	59.6	76.7	63.5	67.7
Men with two or more wives deserve to get AIDS	52.9	59.5	42.6	49.5	49.3	55.1
HIV+ women should not have children	35.3	41.2	23.9	36.9	34.4	35.9
<b>Mean Scores</b>	<b>58.6</b>	<b>63.8</b>	<b>48.4</b>	<b>60.1</b>	<b>57.8</b>	<b>59.1</b>

The mean scores for blame, shame and judgement was 58.6. The mean score for Somaliland was 63.8; Puntland (60.1) and SCS (48.4), as shown in figure 2.

**Figure 2: Stigma index- Shame, blame and judgement**



### 3.1.3 Enacted Stigma

At the family level, PLHIVs were disowned by family members including parents, siblings and children. Cases of divorce and separation were rampant not only among discordant couples but even among concordant couples, especially where blames were shifted to one of the spouses. From the survey, 42.7% of the PLHIVs had at least once been abandoned by their spouses and 56.0% isolated in their household.

Asha (not real name) was diagnosed with HIV in 2013. When she disclosed her HIV status to the family, her father disowned her and none of the families wanted to be associated with her. She was locked in a room for several days before a well-wisher requested the family to allow Asha into her custody. The father 'donated' her and instructed the new keeper that he did not want to see her again, since the family was not happy to be associated with evil. The situation at the well-wisher's custody was not any better. Asha continued to be stressed and experienced a lot of weight loss. In 2014, Asha learned of one of the PLHIV networks and became a member of the Network. Asha confesses finding comfort in the Network after going through peer counselling that reassured her and enabled her regain confidence. *'I had lost hope after all the stigma that I faced. I lost over thirty kilograms in few months due to stigma. I am glad I joined the network as I have since gained back my weight, from fifty two kilograms when I joined to eighty kilograms now.'* - ASHA

About 47.5 % of the PLHIVs had been once or more times abandoned by family or sent away from the village; 34.5 % could not be touched by their spouses after they tested positive or after disclosing their status; 45.7 % had their partners leave after they tested positive or after disclosing their HIV status. Some 59.2 % felt they were no longer visited or less visited by family and friends.

Violence against PLHIV was manifested at the family/ household level, with PLHIVs thrown out of their residence, disinherited of their property and denied access to family resources. At least 58.5% of the PLHIVs had either been teased or sworn at, and 51.1 % had at least once been treated with violence.

Violation of PLHIV rights was not uncommon, with 28.3 % of the survey respondents indicating they had their property taken away, while 30.7 % had at least once been denied religious rites/services, and 25.5% had been physically assaulted. Gossip about PLHIVs was rampant, with 70.5 % of PLHIVs having encountered gossip in the community. Some 47.3% of the PLHIVs had either lost customers to buy

produce/goods or lost a job, and 34.8 % had been denied promotion or further training due to their HIV status. From the group discussions, both with PLHIVs and with the general population, it emerged that PLHIVs were not often allowed to rent office spaces or residential places. According to the survey results, 57.3 % of the PLHIVs had either lost housing or had not been able to rent housing as a result of their HIV status. Manifestation of enacted stigma occurred in various other ways that included denial of leadership positions, discrimination at the service delivery points, in addition to self-stigma enacted by persons living with HIV, all as discussed below:

Denial of leadership positions/ responsibilities: Findings from the interviews with PLHIVs and from the discussions with the general population indicated that the PLHIVs were denied leadership opportunities in the community. The community perceived PLHIVs as people without moral standing and therefore did not deserve leadership positions. The community also considered PLHIVs as people who would use their leadership positions to infect others with the virus and provide opportunities for other PLHIVs to transmit the virus in the community. Self-stigma among PLHIVs also contributed to their exclusion from leadership positions, with many opting not to seek such positions as a result of self -stigma. About 55.9% of the PLHIVs had been excluded from social gatherings, as a result of their HIV status, and 61.7 % lost respect within the family and/or community

Stigma and discrimination at the service delivery point: HIV stigma and discrimination at the service delivery points was identified as an issue, through the FGDs with the PLHIVs and through interviews with PLHIV Networks. It also emerged from the KIIs with the health service providers and health planners.

- 37.6 % PLHIVs given poorer quality health service as a result of their HIV status
- 36.4% PLHIVs delayed to receive healthcare or received inferior care

Persons tested positive for HIV were discriminated and were either provided with sub optimal quality health services or in certain instances denied health services. Most cited cases revolved around delivery assistance for PLHIVs and surgical procedures. As a mandatory requirement, clients were subjected to HIV tests prior to surgical procedures. According to both the PLHIV discussants

and interviews with PLHIV Network Officials, majority of private healthcare providers did not perform the surgical procedures when the clients tested positive. One PLHIV Network recounted instances in which some health facilities provided service provision kits to the Network, so that the Network could instead provide services to those diagnosed with HIV at those health facilities. Some service providers

A pregnant woman was diagnosed with HIV during her routine antenatal care visits. Not of the healthcare workers at the health facility wanted to attend to her. She visited three other health facilities before ending up with a still birth due to delayed attendance. (PLHIV Network FGD participants)

failed to disclose HIV status to the clients once tested positive and did not provide the necessary referrals for comprehensive care and support services. The public sector was not spared, and pregnant women did not receive quality services when they tested positive for HIV. From the survey, 37.6 % of the PLHIVs had been given

poor quality health services, at least once, as a result of their HIV status, while 36.4 % had at least once been delayed to receive healthcare services or received inferior care.

According to the PLHIVs, the health providers did not maintain confidentiality of client information. In some instances, patients in inpatient facilities (wards) vacated the facilities after they received information that one or some of the clients sharing the facilities was HIV positive. Fear of confidentiality loss was one reason the communities did not seek HCT services from HCT centers in their neighborhood.

HIV stigma and discrimination enacted by the healthcare worker was manifested both in the private and in the public health facilities. The magnitude was however reported by PLHIVs to be higher in the private health facilities.

From the survey, 65.9% of the PLHIVs had disclosed their HIV status to a health worker in local health facility closer/near where they lived. A higher percentage of male PLHIVs (69.1 %) had disclosed their status to a health worker in local health facility closer/near where they lived, than the female PLHIVs (63.9 %). The HIV status of 24.8 % of the PLHIVs had been disclosed by a healthcare worker without their consent. This kind of disclosure was experienced by a higher proportion of the PLHIVs in Puntland (37.9 %) than in Somaliland (22.5 %) and SCS (23.0 %).

**Table 7: Non consented disclosure of PLHIV status to a third party**

	Response	Overall	Overall (Male) %	Overall (Female) %	Somaliland	SCS	Puntland
Has a health care worker ever told other people about your status without your consent?	Yes	24.8	23.8	25.4	22.5	23.0	37.9
	No	67.2	65.2	68.4	71.2	63.5	59.2
Has your HIV status ever been revealed without your consent?	Yes	32.5	29.1	34.6	29.0	44.8	19.4
	No	61.5	66.0	58.8	63.5	50.4	77.7

Self-Stigma among PLHIVs: Many PLHIVs in Somali suffer denial, not accepting their status since ‘they are not evil and do not deserve punishment from Allah’. At the individual level, many PLHIVs declined to disclose their status even to the closest family members, friends and relatives. The PLHIV discussants indicated that they felt ashamed of themselves due to community perceptions about HIV and as a result, many of them kept off public/ social events. For fear of making their HIV status public, some senior government officers resorted to using PLHIV Networks to receive their medications while others opted to seek ART services from neighboring countries. This was according to findings from the FGDs with PLHIV Networks. Locally, PLHIVs opted to seek services from distant ART Centers in order to avoid close relatives and friends. At the ART Centers, some PLHIVs registered with names different from their real names, so that they are not identified by those known to them. When visiting the ART Centers for services, the PLHIVs used face masks, so that they are not noticed by those who knew them.

### **3.2 Factors that perpetuate or mitigate stigma associated with HIV/AIDS.**

#### **3.2.1 Myths and misconceptions about HIV/ AIDS**

Stigma and discrimination against persons living with HIV, in the Somali community is associated with myths and misconceptions about HIV/ AIDS. The myths and misconceptions about HIV infection, were mainly as a result of limited knowledge on the medical perspectives of HIV transmission and treatment, among the general population of Somali. The interpretations of HIV/ AIDS in the social and religious domains overshadowed the medical understanding of its transmission and treatment. Both at the household level and in the community in general, PLHIVs were considered immoral and evil people who were subjected to punishment by Allah.

The community perceives the PLHIVs as immoral and people who have deviated from the religious norms and therefore deserve punishment by Allah. For one to be infected with HIV virus, the person must have engaged either in fornication or extramarital sexual intercourse. From the spiritual perspective, the

“I understand that there is a medical perspective to HIV, and that one can be infected with the virus through other mechanisms different from sexual intercourse. In the cases of transmission through other modes, different from sexual intercourse, I think that Allah is testing the person. If he goes on infecting others, then Allah will send a bigger wrath that will wipe him with his entire family. If however he remains obedient, then he will be healed’. Religious Leader- Hargeisa

community described these sexual acts as ‘illegal’ and ‘unholy’ and anyone who indulged in such practices would eventually face the wrath of Allah. This perception was escalated by the fact that majority of the religious leaders, who are the most trusted sources of information, shared the same view

Community perceptions that HIV infection is synonymous with death is a driving factor that propagated HIV stigma and

discrimination. Many people in the community perceived HIV/ AIDS as the leading killer in the world. Stigma and discrimination was mainly as a result of two factors of knowledge and awareness gaps, and that included: 1) PLHIVs are evil persons and people did not want to associate with evil; 2) HIV is a death sentence that can be passed on to others who come into contact with PLHIVs and should therefore be avoided at full length.

As a result of the myths and misconceptions about HIV, some PLHIVs opted out of medication to seek alternative healing through traditional medicine and prayers for spiritual healing. A mixture of camel milk and urine was mentioned both in the FGDs with the PLHIVs and in the FGDs with the general population as one of the alternative medicine sought by PLHIVs. From the FGDs with PLHIVs, however, many persons living with HIV believed that HIV is manageable if one adheres to ART. To the PLHIVs, HIV condition is not as terrifying as it is to the general community that is less knowledgeable on HIV treatment.

### **3.2.2 Inappropriate HIV/AIDs prevention messages**

Inappropriate prevention messages have been cited to further escalate stigma and discrimination against PLHIVs. According to the discussants in the FGDs with PLHIVs and with the general population, some messages tended to invoke fear and prejudice. Messaging by the religious leaders, for example, revolved around the association of PLHIVs with evil, mainly encouraging the community to avoid premarital and extramarital sex as the only modes of HIV transmission. The PLHIVs were therefore judged as those who had engaged in either of the two ‘vices’. According the messages conveyed in some IEC materials, HIV and death were almost synonymous. The messages were scary and the audience was compelled to avoid contact with PLHIVs to the greatest extent possible. Some of the messages identified included:

- Posters of thin people accompanied by HIV messages- ‘Stop HIV’
- ‘Be cautious of HIV the same way you would be cautious of Alshabab’
- HIV does not infect persons of good faith- messaging by religious leaders
- Standalone messaging ‘people should get married legally to avoid HIV’

### **3.2.3 Unpreparedness of the healthcare work force**

From the interviews with the PLHIV Network members, there was a lot of focus on service coverage through establishment of ART Centers and training of healthcare workers on clinical perspectives of HIV treatment. In addition, emphasis had been on service provision at the ART Centers, while not considering that the healthcare workers in the general (non- ART Centers) health facilities, also provided services to PLHIVs and other members of the community who had not taken HCT, but who lived with the virus. Healthcare worker attitude escalated stigma manifestation, especially considering that the service providers belonged to the same community with deeply rooted PLHIV stigma and discrimination. Programs to strengthen preparedness of the healthcare workforce in provision of client friendly services to PLHIVs had not been emphasized. In the perception of the PLHIVs, there were no standard guidelines on how to handle newly diagnosed PLHIVs and each service provider handled PLHIVs in own preferred way. On further probe, the guidelines referred to in this case were those that should be used in the general service delivery outlets, so that once a client is diagnosed with HIV, there are standard procedures to be followed, including for surgical procedures. This thought was echoed in the interviews with some of the service providers who agreed that healthcare workforce was ill prepared to provide surgical procedures to PLHIVs, especially due to limited availability of protective equipment and skill gaps. The unpreparedness of the healthcare worker is considered in terms of limited technical capacity to handle PLHIVs without fear of contracting HIV. The health systems is therefore ill prepared to protect health worker against HIV infection. By extension therefore, HIV service integration remained low, the reason why healthcare workers declined to provide services to those diagnosed with HIV.

### **3.2.4 Inadequate distribution of care and support services provided through ART Centers**

While ART Centers mainly serve as access points for care and treatment of PLHIVs, the presence of the Centers in a location also served as a source of information for the general public. The presence of the Centers signified that there is a medical dimension to HIV, hence demystifying some of the community perceptions about HIV. These Centers were however noted to be limited in number and in distribution across SCS, Puntland and Somaliland. From the discussions with PLHIVs and the general community, and from the interviews with the various stakeholders, the available ART Centers were inadequate in number and were sparsely distributed, with biased concentration in Urban Centers. As a result, communities in remote settings were less likely to interact with these facilities and were therefore not in a position to learn more about the medical perspectives of HIV treatment.

### **3.2.5 Inadequate involvement of PLHIVs in planning and decision making**

AIDS commissions are the coordinating institutions for HIV program response in SCS, Puntland and Somaliland. The main roles of the HIV/ AIDS commissions is to coordinate HIV activities and to support monitoring and evaluation of HIV programs. The coordination roles were however concentrated at the federal levels and minimal or absent at the district levels. The operations of the commissions were further impaired by inadequate financial resources. In all cases, the government resource allocation was primarily for support of operational activities and little or none for implementation of programs. The role of the Commissions remained relevant in coordinating HIV response across government agencies under different Government Ministries and by other stakeholders including the Private Sector and the Civil Society Sector.

To some extent, the Commissions had worked closely with PLHIVs through the existing PLHIV Networks, to ensure participation and involvement of PLHIVs at the community level and in the national response through organized groups. The contribution by PLHIVs and civil society in general to decision making is however limited by their inadequate capacity to engage. Empowerment of the PLHIV Networks would ensure they have the requisite capacity to support anti stigma initiatives at program and at policy levels, while engaging with other relevant institutions. Limited engagement of PLHIVs in health service planning and service delivery was noted in the discussions with PLHIVs as one of the reasons behind stigma and discrimination at the service delivery points. PLHIVs were for example happy to be served by service providers living with HIV.

### **3.2.6 Low PLHIV Network activities**

The development of PLHIV networks was at various stages across the geographical divide. Two networks had been established, South Central Somalia PLHIV Network in SCS and Talowadag in Somaliland while none had been established in Puntland. The PLHIV Networks had demonstrated significant response in addressing the plight of PLHIVs, working closely with the Integrated Comprehensive Care and Support Centers (IPTCS), Government Ministries, NGOs and CBOs. Some of the achievements of the Networks included: formation of support groups, provision of counselling services, delivery of ARVs to network members in the rural settings and homebound ART Center clients, referrals and linkages of PLHIVs with services. The PLHIV Networks also supported livelihood access for PLHIVs through provision of food commodities to members and their households, and through provision of school fees for children from affected families. The Networks facilitated relocation and provided shelter to members who became homeless as a result of HIV/ AIDS stigma & discrimination.

The Networks provided an institutional platform through which the PLHIVs could engage with the relevant government agencies. Representatives of the networks engaged with the government departments in the ongoing discussions regarding HIV policies, legal and institutional environment. The networks also worked closely with development partners in designing and implementing HIV/AIDS related programs, while advocating for stakeholder responses to the plight of PLHIVs.

While the progress made by the PLHIV Networks, where the Networks exist, remains impressive, a number of gaps still limited their potential in responding to the needs of PLHIVs. The convening powers of the Networks were weak and their mobilization of the relevant stakeholders to rally support for championing PLHIV activities were inadequate. The role of the Networks were concentrated in urban settings, mainly at the Federal levels. The Networks did not have capacity to form and manage branches at district levels and other lower levels. As a result, PLHIV activities such as peer education, support group formation, counseling and referrals, among others, at the grassroots were limited in number, distribution and quality. Financial resources were inadequate and the networks did not have diversified sources of funds. The resource mobilization capacity was minimal, with no clear resource mobilization strategies and human resource pool to lead resource mobilization processes.

The scope of activities implemented by the Networks were limited by low financial and human resource capacities of the Networks. Due to inadequate resources, the Networks could not attract and retain qualified staff for the relevant staff portfolios. Very good organograms existed, with relevant staff positions that had not been actualized. There was limited capacity to implement relevant programs, and to attract

and absorb funds for implementation of programs. The absence of a PLHIV Network in Puntland was a glaring gap that made the region lag behind in championing PLHIV needs.

### **3.2.7 Inadequate policy, legal and institutional infrastructure for PLHIV Rights**

Violation of PLHIV rights was escalated by weak policy, legal and institutional mechanisms to address the rights of PLHIVs. HIV policy formulation in Somali was in diverse stages across SCS, Puntland and Somaliland. Both SCS and Puntland had draft HIV policies that were due for ratification and approval. In both cases, and especially at the SCS, the process of ratification had taken longer than was expected. The delays in both cases were attributed to high staff turnover within the relevant approval/ ratification departments. Lack of HIV/ AIDS champions at the higher level of governance, also played part. In Somaliland, the HIV policy in place was developed in 1999. There were plans to review the policy, considering that transformations have taken place over the 16 years period since the implementation of the policy started.

The legal framework for HIV/AIDS was weak in SCS, Puntland and Somaliland. In all cases, there were draft HIV bills that were due for enactment in parliament. Like in the case of the policies, the enactment of the bills had been pending over a long period of time. Even with good policies in place, it will not be possible to access justice for PLHIVs if the legal framework is not strengthened. Further still, justice can only be assured if the regulatory authorities, including the judiciary and law enforcement authorities are empowered to implement the necessary laws and policies.

The fact that some HIV polices have not been ratified and the fact that the HIV bills have not been enacted are indicative of the unprepared legal and regulatory environment. As a result of weak HIV policy and legal frameworks, the PLHIVs were unable to access justice in instances where their rights were violated. The main issues of discrimination experienced by PLHIVs and that required policy and legal redress included: denial of healthcare services; loss of employment; discrimination in educational institutions; denial of access to public facilities; denial of property rights; abuse of right to confidentiality of health information and domestic violence. Apart from its impact on the PLHIVs, the effect of inadequate policy, legal and regulatory framework is also manifested in the case of the general population that are exposed to HIV infection. Strengthening these frameworks will therefore be beneficial both to the PLHIVs and the general population and will go a long way to confirm the government's commitment in ensuring quality life for its people.

### **3.2.8 Weak post HCT linkages with care and treatment**

Weak post HCT linkages of PLHIVs with care and treatment services as a result of unstructured referral systems was also noted as a barrier to Service access and utilization. As a result of these gaps in referrals and linkages, many people who tested positive for HIV did not receive timely psychosocial support and succumbed to self-stigma. PLHIVs who did not receive care and treatment services often experienced deteriorated physical strength and manifestation of symptoms that exposed them to HIV related stigma and discrimination. According to the PLHIV discussants in the FGDs, the urge to prevent physical bodily changes resulting from HIV symptoms is a motivation to remain committed to treatment. The groups agreed that HIV is a manageable disease that they have accepted to live with.

### 3.2.9 Progress and opportunities in the fight against HIV stigma

The fact that relevant government ministries recognize PLHIVs and provide them with support through their networks, e.g. training opportunities and nutritional support, was acknowledged as a very important step towards mitigating HIV stigma. According to the PLHIV Network officials, there was growing good will from political leaders (MPs and Senators) to support the HIV policy processes. There was also commitment by the respective Ministries of Health Officials to fast track the finalization of ongoing HIV policy processes. Also seen as an opportunity in the fight against HIV stigma and discrimination is the possibility of senior officers disclosing status and going public once there is policy in place.

### 3.3 Effects of stigma and discrimination on HIV prevention, treatment care and support services

#### 3.3.1 Stigma leads to low uptake of HCT

Findings from the FGDs, both with the PLHIVs and with the general community, suggest that many of the community members are not aware of their HIV status. According to the discussants in the FGDs, low HCT uptake was as a result of low HIV knowledge, especially in regard to the association of HIV infection with religion. The perception that HIV infection did not have any medical relevance, and that it was an evil disease, prevented many people from seeking HIV testing services. Community sensitization for HCT uptake and linkages between communities and testing Centers through referrals were inadequate, and availability of HCT services limited by their sparse distribution. Many people did not know they were living with HIV and were not available for treatment and support

#### 3.3.2 Stigma leads to non-disclosure or delayed disclosure of HIV Status

As a result of HIV related Stigma and discrimination, many PLHIVs did not disclose their HIV status. It emerged from the focus group discussions with the general population, that many PLHIVs were not known in the community. From the survey, 71.3 % of the respondents were worried that those who knew their HIV status would disclose that to others. More female PLHIVs were worried about third party disclosure than were the male PLHIVs (73.7 %; 67.4 %). Overall, 90.1 % of the respondents were careful to whom they disclosed their status (Female: 91.5 %; Male: 87.9 %). On the other hand, 87.3% of the PLHIVs thought that, telling someone that they are HIV positive was something very risky (Male: 84.0 %; Female: 89.3 %). Nearly all the PLHIVs made a big effort to make sure that their HIV status is kept a secret (92.8 %). Again, female PLHIVs were more likely to make a big effort in keeping their HIV status secret (94.4 %) than were the male PLHIVs (90.1 %).

**Table 8: Effect of stigma on disclosure**

Effect	%
PLHIVs worried about third party disclosure	71.3
PLHIVs careful on whom they disclose their status to	90.1
PLHIVs who thing disclosing their HIV status is very risky	87.3
PLHIVs making a big effort to keep their status a secret	94.4

A large proportion of PLHIVs (87.5 %) had disclosed their HIV status to someone, with 86.6% of PLHIVs in Somaliland; 89.6% of PLHIVs in SCS and 86.4 % of PLHIVs in Puntland. Disclosure rate did not differ significantly between the female PLHIVs (87.6 %) and the male PLHIVs (87.2 %). PLHIVs disclosing their status within six months after diagnosis was 62.8 % while 14.4 % disclosed their status after one year. Another 15.2 % of the PLHIVs had however not disclosed their HIV status to anyone. The proportion of PLHIVs disclosing their status within six months was lower in Puntland (49.5 %) than in Somaliland (62.4

%) and SCS (69.6 %). In addition, a bigger proportion of PLHIVs in Puntland (18.4 %) had never disclosed their HIV status to anyone, compared to Somaliland (14.6 %) and SCS (14.3 %). Table 9 shows the variations in the period within which the PLHIVs disclosed their status.

**Table 9: Period of disclosure among PLHIVs**

Period of disclosure	Overall (%)	Somaliland (%)	SCS (%)	Puntland (%)
Within six (6) months	62.8	62.4	69.6	49.5
After 1 year	14.4	17.7	11.3	7.8
More than 1 year	3.7	4.8	1.7	3.9
Never	15.1	14.6	14.3	18.4
No Response	4.0	0.5	3.0	20.4
Total	100.0			

More PLHIVs (45.7 %) had disclosed their HIV status to their family members than they had disclosed to anyone else. About 20.8 % of the PLHIVs had disclosed their status to their spouses. More male PLHIVs (26.6 %) disclosed their HIV status to their spouses than the female PLHIVs (17.3 %). In the contrast, more female PLHIVs (48.1 %) disclosed their status to their families than the male PLHIVs (41.8 %). Similarly, about 11.5 % of the female PLHIVs against 7.4 % male PLHIVs had disclosed their status only to a healthcare provider. The proportion of PLHIVs disclosing their status to a community member or a friend was higher for males (7.8 %) than for the female PLHIVs (6.1 %).

Majority of those who had disclosed their HIV status to a third party in Puntland had only done so to a healthcare provider (31.1 %). However, Puntland had the highest proportion of those who had disclosed their HIV status to their spouses (26.2 %) compared to Somaliland (20.6 %) and SCS (18.7 %). Table 10 provides information on disclosure by category.

**Table 10: Disclosure of HIV status to a third party**

Who have you, told your HIV status?	Overall (%)	Overall (Male) %	Overall (Female) %	Somaliland (%)	SCS (%)	Puntland (%)
Spouse/Partner	20.8	26.6	17.3	20.6	18.7	26.2
Family	45.7	41.8	48.1	51.1	45.7	24.3
Community member/ Friend	6.1	7.8	5.1	4.6	9.6	4.9
Only health providers	9.9	7.4	11.3	3.6	11.7	31.1
No Response	17.5	16.3	18.2	20.1	14.3	13.6

Disclosure of HIV status to a sexual partner was highest in Puntland (62.1%) and lowest in Somaliland (38.4 %), while in SCS, 60.0 % of the PLHIVs had disclosed their status to a sexual partner. In terms of gender comparisons, more male PLHIVs (57.1 %) than female PLHIVs (42.9 %) had disclosed their HIV status to a sexual partner.

**Table 11: Disclosure of HIV status to a sexual partner**

		Overall (%)	Overall (Male) %	Overall (Female) %	Somaliland (%)	SCS (%)	Puntland (%)
Have you disclosed your HIV status to any of your sexual partners?	Yes	48.3	57.1	42.9	38.4	60.0	62.1
	No	49.6	40.8	54.9	59.7	37.8	35.0
Disclosed to all sexual partners		4.8	6.4	3.8	6.7	2.2	2.9
Only current partner		37.6	43.3	34.2	29.3	44.8	55.3
Only past partner		5.2	6.4	4.5	2.6	10.0	4.9
Never		47.1	38.3		59.5	37.4	18.4

### 3.3.3 Stigma leads to loss of family and friends (Social exclusion)

The social effects of HIV Stigma and discrimination included the loss of family and friends. Many PLHIVs relocated to distant places when discriminated by family and friends. Some PLHIVs, due to self-stigma, did not want to be identified in their resident communities and opted to isolate themselves, in order to avoid gossip. The effect of the relocation and self-isolation is manifested in depression suffered by PLHIVs and

**Table 12: Social exclusion of PLHIVs**

Effect of stigma	%
PLHIVs loose love and guidance in the family	85.9
PLHIVs become lonely	90.3
Stigma weakens family bond	89.3
PLHIVs wish they had not married	66.5
Stigma creates family barriers	81.2

in loss of psychosocial support from close family members, relatives and friends. It also comes with an economic impact since the PLHIVs have to incur expenses in moving and establishing new residence. From the survey, 85.9 % of the PLHIVs reported that PLHIVs lost love and guidance in the family, and 90.3 % reported that they became lonely as a result of stigma and discrimination. Another 89.3 %

reported that HIV stigma and discrimination led to weakened family bonds. A larger proportion of female PLHIVs than male PLHIVs (Male (63.1 %); Female (68.6 %)) indicated that PLHIVs wished they had not married. Overall, 66.5 % of the respondents indicated that the PLHIVs wished they had not married.

### 3.3.3 Stigma leads high service seeking costs and to non- adherence to ART Treatment

Findings from the FGDs revealed that some PLHIVs stopped medication as a result of stigma. Some PLHIVs also opted to seek care and support from distant ART Centers to avoid meeting those known to them. This came with additional cost of long distances travelled for ART services that could otherwise be obtained from nearby ART Centers. From the survey, 77.9 % of the respondents agreed that PLHIVs spend lot of funds travelling to access treatment far away from their locality (Male: 80.9 %; Female: 76.1 %). On the other hand, 79.3 % of the PLHIVs reported that stigma affects adherence to medicines. On the other hand, denial led to many PLHIVs not initiating medication and others stopping treatment. The effect of denial includes delayed medication and delayed access to social support services.

### 3.3.4 Stigma causes depression and sometimes suicidal ideation

Both denial and non-disclosure led to depression and in some cases suicide. According to 75.9 % of the PLHIVs, stigma had led to high death rates in the community. This view was shared by 73.0 % of the male PLHIVs and 77.6 % of the female PLHIVs. Another 81.2 % reported that PLHIVs die early as a result of stigma related stress, while 77.5 % indicated that stigma could lead to suicide among PLHIVs. Early death of PLHIVs came with an increase in the number of OVCs, with 76.1 % of the PLHIVs owning that stigma led to increase in the number of OVCs.

### 3.3.5 Stigma leads to vengeance and more HIV infections

As a result of HIV stigma in the community, some PLHIVs engaged in unprotected sex with the intention

“PLHIV are highly stigmatized and discriminated by the community, they are cruel to the community and spread HIV in the community”. FGD Discussant- GP

of infecting others. From the survey, 84.9 % of the PLHIVs agreed that stigma leads to high rate of HIV infection. According to 76.7 % of the respondents, PLHIVs who are stigmatized may turn violent and/ or indulge in vengeance

### 3.3.6 Stigma leads to loss of work force in the community

Discrimination against PLHIVs led to loss of both skilled and non-skilled human resources in the community. The contribution of PLHIVs to community development was therefore lost as a result of stigma and discrimination. PLHIVs believed that stigma had led to increased workload. From the survey, 77.9 % of the PLHIVs, 80.9 % of male PLHIVs and 76.1 % of the female PLHIVs shared the view that stigma had led to increased work load. Some 75.6 % of the PLHIVs (Male: 77.3 % and Female: 74.6 %) thought that the community had lost advisors as a result of HIV stigma and discrimination.

### 3.3.7 Stigma leads to loss of access to livelihoods for PLHIV and their households

Workplace related HIV stigma and discrimination was cited across all the group discussions and in the Key informant interviews as one of the factors that led to loss of livelihoods among PLHIVs. Many PLHIVs, including Government Officials, in certain instances, lost their jobs after their status was known. Fear of contact with PLHIVs and fear of sharing facilities with PLHIVs was identified as a barrier to livelihoods access by PLHIVs. According to the PLHIV focus group discussants and general population focus group discussants, majority of the PLHIVs and their families do not have requisite skills for other gainful engagement, whether in self-employment, business or through other income generating activities (IGAs). Where such skills existed, other barriers including financial access and mentorship lacked, making it difficult to initiate such ventures. As a result of poverty, many PLHIVs and their households could not afford food for household consumption. Many PLHIVs relied on food distribution supported by the government and development partners, to meet their nutritional needs and the needs of their households, although the distribution was not predictable and the quantities were not sufficient to meet the demand.

## 3.4 Quantitative stigma and discrimination index (SDI)

Stigma index was computed using 33 items categorized into 5 categories, each of the five categories included a composite of stigma indicators corresponding to the categories. The five broad categories included: reservations on HIV status disclosure, non-invasive contact with PLHIV, shame blame and judgment, enacted stigma and cumulative effect of stigma. The index was estimated on a scale of 1-100 and each of the five categories was assigned the same value (20 units per category).

### 3.4.2. Overall Stigma Index

The scores for each category was computed using individual variable responses under each category and provided the following values: non-invasive stigma (10.0); reservations on HIV/ AIDS disclosure (17.0); Shame blame and judgment (11.8); enacted stigma (7.0); experience of cumulative stigma effect (16.0). The overall stigma index for the country was hence estimated at 61.8

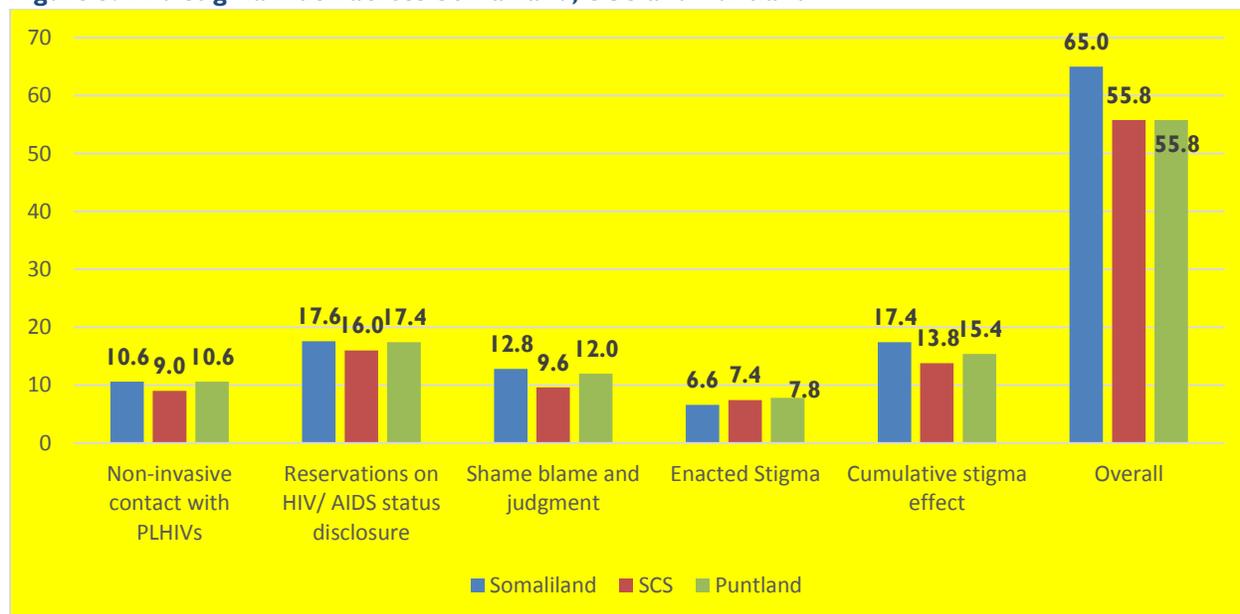
**Table 13: Overall stigma Index**

Form of Stigma	Score	Unit value	Index
Non-invasive contact with PLHIVs	0.50	20	10.0
Reservations on HIV/ AIDS status disclosure	0.85	20	17.0
Shame blame and judgment	0.59	20	11.8
Enacted Stigma	0.35	20	7.0
Cumulative stigma effect	0.80	20	16.0
<b>Overall</b>		<b>100</b>	<b>61.8</b>

### 3.4.2. Comparison of Stigma Index across the regions

Somaliland had the highest stigma index rating of 65.0. Puntland and Somalia had a similar rating of 55.5 each. According to some stakeholders, one would expect tower stigma levels in Somalia and Somaliland than in Puntland, as a result of the established PLHIV Networks. On the other hand, some stakeholders also opine that the PLHIV Networks have not scaled u activities to a level that can effect a significant change. The high HIV Stigma for Somaliland may be as a result of the high level of interactions in the region. The possibility of PLHIVs experiencing stigma and discrimination is higher when they interact more often with other members of the community, than in instances where their interactions are limited.

**Figure 3: HIV stigma index across Somaliland, SCS and Puntland**



The stigma index for the female PLHIVs was higher than that of the male PLHIVs. The indices were 63.0 and 60.6 for female and male PLHIVs respectively. The female PLHIVs had highest index in each of the 5 categories of analysis. Table 14 shows the comparison on indices between the male and female PLHIVs

**Table 14: Indices for male and female PLHIVs**

Form of Stigma	Index by gender	
	Male	Female
Non-invasive contact with PLHIVs	9.4	10.6
Reservations on HIV/AIDS status disclosure	16.6	17.4
Shame blame and judgment	11.6	11.8
Enacted Stigma	7	7.2
Cumulative stigma effect	16	16
<b>Overall</b>	<b>60.6</b>	<b>63.0</b>

Tables 15 to 19 show the analysis for each of the items used in the computation of the stigma index. In cases where Likert scale items were used to measure the stigma index, the responses were weighted to generate the index.

**Table 15: Experiences of fear of HIV infection from non-invasive contact**

	Overall	Overall (Male)	Overall (Female)	Somaliland	SCS	Puntland
People not willing that I cook at functions	50.5	43.8	54.5	52.9	44.5	54.0
People not willing that I share meals at functions	52.2	48.7	54.4	53.9	47.6	56.3
People not willing that I serve guests meals	49.7	45.9	52.0	50.9	44.7	56.0
People not willing that I share beddings	50.6	46.6	53.0	54.8	44.1	47.9
People not willing that I share soaps	48.8	44.2	51.7	55.1	36.1	52.0
People not willing I shake hands	50.3	50.6	50.2	48.8	51.7	53.1
<b>Average</b>	<b>50.4</b>	<b>46.6</b>	<b>52.6</b>	<b>52.7</b>	<b>44.8</b>	<b>53.2</b>

**Table 16: Disclosure related stigma**

	Overall	Overall (Male)	Overall (Female)	Somaliland	SCS	Puntland
I am worried thinking that those who know I have HIV will tell that to others	71.3	67.4	73.7	75.5	63.0	72.8
I would like it if my family and close friends keep my HIV-positive status a secret	84.4	85.1	84.0	84.4	81.7	90.3
I am very careful to whom I tell that I am HIV-positive	90.1	87.9	91.5	93.5	85.2	87.4
To tell someone that I have HIV is something very risky	87.3	84.0	89.3	90.2	81.7	88.3
I make a big effort to make sure that my HIV is kept a secret	92.8	90.1	94.4	94.5	87.8	97.1
<b>Average</b>	<b>85.2</b>	<b>82.9</b>	<b>86.6</b>	<b>87.6</b>	<b>79.9</b>	<b>87.2</b>

**Table 17: Shame, Blame and Judgement**

	Overall	Overall (Male)	Overall (Female)	Somaliland	SCS	Puntland
HIV is a punishment from God	77.9	78.4	77.6	81.5	79.6	59.2
Some people think HIV is a punishment for bad behaviour	61.9	60.3	62.8	68.6	48.7	64.1
Most people with AIDS deserve what they get	57.9	56.4	58.8	61.4	40.0	83.5
It is women prostitutes who spread HIV in community	65.3	68.8	63.2	74.1	54.3	54.4
People with HIV are promiscuous	51.5	51.1	51.7	57.3	38.7	56.3
People with HIV should be ashamed of themselves	66.1	63.5	67.7	67.1	59.6	76.7
Men with two or more wives deserve to get AIDS	52.9	49.3	55.1	59.5	42.6	49.5
HIV+ women should not have children	35.3	34.4	35.9	41.2	23.9	36.9
<b>Average</b>	<b>58.6</b>	<b>57.8</b>	<b>59.1</b>	<b>63.8</b>	<b>48.4</b>	<b>60.1</b>

**Table 18: Experiences of enacted stigma**

	Overall	Overall (Male)	Overall (Female)	Somaliland	SCS	Puntland
Been excluded from a social gathering	43.9	43.4	44.1	44.2	40.6	49.8
Been abandoned by your spouse/partner	33.7	33.9	33.5	34.0	29.9	40.1
Been isolated in your household	44.5	45.2	44.1	40.7	46.0	56.6
No longer visited/ visited less frequently by family/ friends	44.2	42.4	45.3	44.7	39.1	53.1
Been teased, insulted or sworn at	45.9	42.8	47.8	43.7	47.9	50.8
Lost customers to buy produce/goods or lost a job	36.5	35.9	36.8	35.0	31.9	52.7
Lost housing or not been able to rent housing	46.6	46.2	46.9	43.8	45.8	60.2
Been denied religious rites/services	22.1	20.6	23.1	19.8	26.7	21.6
Had property taken away	20.2	19.1	21.0	20.4	22.2	15.5
Been gossiped about	59.0	59.5	58.7	56.4	62.1	62.8
Lost respect /standing within the family and/or community	48.6	48.0	49.0	46.5	48.6	57.0
Been treated with violence	39.4	35.9	41.5	37.3	42.5	41.8
Been given poorer quality health service	25.1	27.5	23.6	22.3	34.6	14.9
Been physically assaulted	18.0	17.3	18.2	16.5	22.2	14.6
Been denied promotion/further training	26.7	31.9	23.5	21.6	30.3	39.1

Been abandoned by family/sent away from the village	39.0	38.2	39.6	35.5	41.4	47.6
Been delayed to receive healthcare or received inferior care	23.8	23.8	23.9	20.4	35.3	12.0
Partner could not touch me after I tested positive or disclosing my status	26.3	25.2	27.0	24.8	25.8	33.3
Partner left after I tested positive or disclosing my status	25.5	23.1	27.0	24.6	26.4	27.6
<b>Average</b>	<b>35.2</b>	<b>34.7</b>	<b>35.5</b>	<b>33.3</b>	<b>36.8</b>	<b>39.5</b>

**Table 19: Perceptions on cumulative effect of stigma**

	Overall	Overall (Male)	Overall (Female)	Somaliland	SCS	Puntland
Because of stigma there is increased work load	77.9	80.9	76.1	83.9	63.5	85.4
Because of stigma, there is high death rate in the community	75.9	73.0	77.6	88.2	59.6	62.1
Because of Stigma, the community has lost advisors	75.6	77.3	74.6	82.0	66.5	69.9
Because of stigma, there is increase in number of OVCs	76.1	76.6	75.9	86.8	60.0	68.9
PLHA who are stigmatized may turn violent, e.g. defile or rape other	76.7	77.7	76.1	83.5	68.7	67.0
Stigma leads to high rate of infection	84.9	84.4	85.3	91.8	73.0	83.5
Due to stigma PLHA loose love and guidance in the family	85.9	85.5	85.9	88.7	81.3	84.5
Due to stigma PLHA become lonely	90.3	89.4	90.8	94.0	83.5	90.3
Due to stigma PLHA there is weakened family bond	89.3	90.1	88.9	92.6	82.6	91.3
Due to stigma PLHA create family barriers	81.2	82.3	80.6	85.6	73.0	91.3
There is too much stress and individual die early	81.2	80.9	83.3	90.6	67.4	82.5
Possibility of committing suicide	77.5	77.0	77.8	81.8	71.7	72.8
PLHA spend lot of funds to access treatment far away from their locality	77.9	80.9	76.1	81.8	72.2	74.8
Due to stigma it affects adherence to medicines	79.3	77.3	80.6	88.5	63.9	76.7
Due to stigma, many PLHA wish they had not married	66.5	63.1	68.6	77.2	50.4	59.2
<b>Average</b>	<b>79.7</b>	<b>79.8</b>	<b>79.9</b>	<b>86.5</b>	<b>69.2</b>	<b>77.3</b>

## **5.0 Conclusions and Recommendations**

### **5.1 Conclusions**

Stigma and discrimination against PLHIVs is very high in Somali, both in terms of self-stigma among PLHIVs and in terms of stigma manifested by the general community against PLHIVs. The main factors behind high levels of stigma include low levels of HIV knowledge and awareness in the community, creating room for myths and misconceptions to thrive in the community. Knowledge and awareness gaps are further confounded by the religious perspectives in regard to HIV transmission and treatment. While efforts have been made at various levels, to address HIV knowledge gaps, results are yet to be realized. Community reach has been low due to inadequate distribution of activities implemented by CSOs, PLHIV Networks and other stakeholders involved in HIV work. In addition, HIV resources were low and the stakeholders did not have the adequate financial and human resources to implement HIV knowledge and awareness programs. While HIV messaging has undergone a lot of transformations worldwide, the prevention messages in Somali still tend to scare the community, rather than provide information that stimulates behavior change without necessarily propagating stigma.

The manifestation of stigma and discrimination against PLHIVs, by the healthcare workers is inhuman and violates the rights of the PLHIVs. Weak human resource capacity, including gaps in client relations and low capacity to provide services without fear of contracting HIV, are the major contributors to this kind of stigma.

The policy environment was not supportive of PLHIV needs. Although there were ongoing initiatives to strengthen the policy environment, pace of these ongoing processes remained low and needed to be fast tracked so that the policies are brought to force. Weak legal and institutional frameworks for enforcement of PLHIV rights is a major enhancer of stigma and discrimination in the republic. Like in the case of policies, the draft bills that exist need to be enacted and relevant institutions strengthened to support their implementation.

The PLHIV Networks have a high potential for fighting stigma and discrimination through engagement with PLHIVs and with the general community. The Networks also have great potential for engaging in the policy processes, program planning and decision making at the National and Sub National levels. They did not however realize their full potential due to their low capacities, limited presence and inadequate resources.

### **5.2 Recommendations**

- I. Support the review and harmonization of HIV prevention and treatment messages, and the development of more relevant and effective messages. Addressing medical perspectives of HIV transmission and treatment may be integrated under sexual and reproductive health messaging in order to gain greater acceptance by the community.

- II. Provide capacity building support to the healthcare workforce, including training on client friendly services and provision of the necessary protective equipment that prevents the risks of healthcare worker from contracting HIV during service provision. It will also be important to provide training on universal precautions for infection prevention to enable the healthcare workers deliver services without fear of contracting HIV.
- III. Strengthen post HCT linkages with care and support. This will help minimize the number of PLHIVs succumbing to denial and self-stigma, by ensuring that the persons testing positive for HIV are linked to the necessary psychosocial support, care and treatment. Strengthening such linkages may require establishment of post HCT support groups and strengthening referral systems among others.
- IV. Strengthen advocacy against HIV stigma and discrimination. The advocacy approach should be innovative and should target key audiences with relevant messages. The campaigns should for example involve religious leaders as key influencers of religious perspectives of HIV. Anti-stigma campaigns should involve the religious leaders as ambassadors of change. Also to be targeted should be the key government officers who are PLHIVs and who may engage as champions against PLHIV stigma and discrimination. The approach should promote magnification of champions within PLHIV communities as role models to address self-stigma issues and show that PLHIVs too can have their rights respected, live with dignity and productive life.
- V. Strengthen PLHIV Networks by building the capacity of the existing Networks in SCS and Somaliland, and by supporting the establishment of a PLHIV Network in Puntland. Capacity strengthening for the Networks should aim at empowering their internal capacities to mobilize and attract resources for HIV programming; expanding their capacities to better coordinate PLHIV activities at the National and Sub National Levels as well as their ability to decentralize their activities for greater reach at the community. This way, the Networks will be able to engage with other CSOs operating at different levels and expand access to care and support services to its members. The terms of reference for the Networks should clearly define their expected roles and the capacity required to perform such roles, so that the capacity building initiatives are tailored to the evident needs.
- VI. Finalize the ongoing policy processes. The relevant government departments should prioritize and fast track the ongoing policy processes. PLHIVs, through their Networks and while working with other stakeholders, should advocate for quick finalization and adoption of the policies. Once finalized, the policies should be disseminated and relevant stakeholders sensitized. Implementation capacities of the relevant stakeholders should also be strengthened to facilitate the implementation of the policies. The PLHIV networks should be supported to monitor the implementation of these policies.

- VII. Strengthen the legal and institutional frameworks for enforcement of PLHIV rights. This should include enactment of the pending HIV bills, followed by sensitization of stakeholders including the PLHIVs and the general community. The relevant institutions expected to enforce the PLHIV rights should be empowered to implement the acts.