



THE ZIMBABWE PEOPLE LIVING WITH HIV STIGMA INDEX



ZIMBABAWE STIGMA INDEX RESEARCH REPORT

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ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ARDeZ	Anglican Relief Development in Zimbabwe
ART	Antiretroviral Treatment
ARV	Antiretroviral
BRTI	Biomedical Research Training Institute
CeSHHAR	Centre for Sexual, HIV & AIDS Research
CSO	Civil Society Organisation
DA	District Administrator
DfiD	Department for International Development
EFZ	Evangelical Fellowship of Zimbabwe
FBO	Faith-based organisations
FGDs	Focus Group Discussions
GALZ	Gays and Lesbians Zimbabwe
GIPA	Greater Involvement of People Living with HIV/AIDS
GNP+	Global Network of PLHIV
HIV	Human Immunodeficiency Virus
IBSR	Inquiry Based Stress Reduction
ICW	International Community of Women Living with HIV/AIDS
IDI	in-depth-interviews
IPPF	International Planned Parenthood Federation (IPPF)
IRiZ	Impact Research International Zimbabwe
MIPA	Meaningful Involvement of People Living with HIV/AIDS
MRCZ	Medicines Research Council of Zimbabwe
MSM	Men who have Sex with Men
NAC	National AIDS Council
NCDPZ	National Council of Disabled Persons of Zimbabwe
NGO	Non-governmental organizations
PA	Provincial Administrator
PLHIV	People living with HIV
PMTCT	Preventing Mother-To-Child-Transmission of HIV
PSI	Population Services International
RDS	Respondent Driven Sampling
SAFAIDS	Southern African AIDS Information Dissemination Services
SAYWHAT	Students and Youths Working on Reproductive Health Action Team
SPSS	Statistical Package for the Social Sciences
SW	Sex Workers
UMC	United Methodist Church
UNAIDS	United Nations Joint Programme on AIDS
UNICEF	United Nations Children's Education Fund
UNFPA	United Nations Populations Fund
Us.	United Societies
ZAN	Zimbabwe AIDS Network

ZDHS	Zimbabwe Demographic Health Survey
ZHAAU	Zimbabwe HIV & AIDS Activists Union
ZIMASSET	Zimbabwe Agenda for Sustainable Socio Economic Transformation
ZIMSTAT	Zimbabwe National Statistics Agency
ZNASP II	ZIMBABWE National AIDS Strategic Plan II (2011-2015)
ZNNP+	Zimbabwe National Network of PLHIV
ZPCS	Zimbabwe Prisons and Correctional Services

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EXECUTIVE SUMMARY

Overview

In February 2013, the Stigma Index Research Advisory Board commissioned Impact Research International Zimbabwe (IRiZ) to carry out the Stigma Index for Zimbabwe study. The study was a ground-breaking research endeavour in Zimbabwe aimed at understanding the nature, experiences, and rates of *HIV-related stigma* and discrimination at a national level, subsequently providing an evidence base that will ultimately lead to implementation of more effective programmes aimed at reducing HIV-related stigma and discrimination as well as ensuring the Meaningful involvement of People Living with AIDS (**MIPA**) principle is enshrined in local, regional and national responses to HIV.

Methodology

The study involved utilization of both quantitative and qualitative data collection methods. A cross sectional survey was conducted through a questionnaire that was administered among PLHIV. The questionnaire that was used is the “People living with HIV Stigma Index”, which was developed by and for gathering HIV-related stigma among people living with HIV. The study was undertaken over a period of about 18 months, and was implemented in all the 10 provinces of Zimbabwe. Three districts were selected from each province.

Qualitative data were collected through FGDs and in-depth interviews with key informants at national, provincial and district levels. In addition, case studies, identified during the data collection process, were documented. Case Studies complimented the quantitative data and served to “bring to life” real-life experiences of individuals who had both positive and negative experiences to share.

A total of 1905 respondents participated in the study; 725 (38%) were male and 1180 (62%) were females. Forty-five percent (n=864) of the respondents were adults aged between 40 – 49 years, 33% (32.9%, n= 626) were adults aged between 30 – 39 years and about 6% (5.8%, n=111) were participants aged 50 years and above. Respondents aged 20 – 24 years and 25 – 29 years constituted 4% and 9% of the sample respectively. Only 3% were youth aged between 15 – 19 years.

Close to 89% of respondents revealed that they did not belong to any of the “key population” categories included in this study. Of the study participants, there were however, more females than males who were members of support groups. Of the 12% of participants who belonged to the key populations, 6% (5.5%, n=104) were people living with disabilities, and 2% (2.2%, n=42) were commercial sex workers. Men having sex with men constituted nearly 2% (1.9%, n=36) of the participants, and another 2% (1.6%, n=30) of the participants were prison inmates.

Major Findings

HIV Related Stigma

- Overall, 65.5% of the study respondents reported that they had experienced one or more forms of HIV-related stigma and discrimination.
- Over half (51.4%) of the respondents reported that they had been gossiped about
- Close to a third (31.2%) reported that they had been verbally insulted, harassed and/or threatened.
- Other forms of HIV related stigma that were reported include: exclusion from social gatherings (21%), physically harassed and/or threatened (19%), discrimination by partners (15%), psychological pressure or manipulation (12.4%), exclusion from family activities (11.7%), exclusion from religious activities or places of worship (10.6%), being physically assaulted (8.6%), sexual rejection (7.5%) and discriminated against by other people living with HIV (7.5%).

Access to work, health and education services

In the 12 months preceding the study,

- Just over thirteen percent (13.1%) had been forced to change their place of residence or denied accommodation.
- Over twenty percent (20.6%) of the respondents reported that they had lost their job or another source of income, while 12.1% were denied employment or work opportunity and 9.1% had their job description or nature of work changed or refused promotion as a result of their HIV status.
- Only 4.1% of the respondents reported that they had been dismissed, suspended or prevented from attending an educational institution as a result of their HIV status.
- On the other hand, 80.6% of the respondents reported that their children had been dismissed, suspended, or prevented from attending an educational institution.

Internalised Stigma and Fears

The following internalised forms of stigma were reported:

Feelings

- 18.9% of the respondents reported that they feel guilty and have low self-esteem because of their HIV status.
- Also, 17.9% said that they blame themselves, while 16.7% feel ashamed, and 16.5% said that they blame others.

Fears

- Over a third (37.2%) of the respondents reported that they fear being gossiped about.
- When asked of their other fears, 17% reported that they were afraid of sexual rejection, while 15.4% said that they feared being verbally insulted.

Rights, Laws and Policies

- Nearly thirty percent (29.5%) of the respondents reported that they had heard of the 2001 Declaration of the Commitment on HIV/AIDS which protects the rights of people living with HIV. Over two thirds (67.5%) of the respondents who had heard of the Declaration of Commitment on HIV/AIDS reported that they had read or discussed the content of the Declaration.
- With regards to hearing of the National AIDS policy, 57.2% of the respondents reported that they had heard about it. Of those who heard about the National AIDS policy, 38.8% of them reported that they had read or discussed its contents.

Effecting Change

- Over half (55.8%) of the respondents reported that they had confronted, challenged or educated someone who was stigmatising and discriminating against them in the 12 months preceding the study.
- Just below three quarters of the respondents (70.8%) reported that they knew of support organisations that they can go to if they experience stigma and discrimination.
- Nearly ninety two percent (91.8%) of the people living with disabilities compared to 75% of men having sex with men, 70.4% of support group members, 53.3% of prison inmates and 46.2% of sex workers reported that they knew of support organisations that they can go to if they experience stigma and discrimination.

Testing and Diagnosis

- Just below a third of the respondents (31.3%) reported that they were tested for HIV because “they just wanted to know; 20.5% reported that they tested because of illness or

death of their partner or family member, while 17.2% reported that they were referred due to suspected HIV related symptoms.

- Over half (51.1%) of the respondents reported that whilst they underwent HIV testing, it was due to pressure from other individuals, 42% of respondents tested on a voluntary basis, 2.4% were coerced into testing, and only 1.8% were tested without their knowledge.
- It is worth noting that 91% of the respondents reported that they had received both pre - test and post - test counselling when they were undergoing HIV testing.

Disclosure and Confidentiality

- Less than five percent (4.3%) of the respondents reported that a health care professional (for example, a doctor, nurse, counsellor) had told other people about their HIV status without their consent.
- The data suggests that most of the people living with HIV and AIDS disclosed their status themselves without interference from a third party.

Treatment

- Overall, 30% described their health status as “fair”, a further 27% said their health was “good”, 20% indicated that their health was “excellent”, 18% reported that their health was “very good” and approximately 4.5% said their health was “poor”.
- The data suggests that most of the respondents have access to ART, regardless of whether or not they are in support groups or are members of key populations. All Prison inmates reported that they had access to ART, sex workers had access to ART 7 times out of ten, and 82% of MSM also reported that they have access to ART.

Having Children

- Eighty five (84.8%) of the respondents reported that they had children. Of these, 83% reported that, after diagnosis, they received counselling on their reproductive options.
- Almost half (42.8%) of respondents were advised not to have children.
- Close to five percent (4.8%) of the female respondents reported that they had been forced to terminate pregnancy.
- With regards to delivery methods, 6.8% of the females reported that they had been coerced by a health care professional e.g. forced to have a caesarean section.
- Just under nine percent (8.9%) of the mothers reported that they had been forced to adopt infant feeding practices wanted by the health care professional who attended to them.

Recommendations

To understand the ways in which HIV/AIDS-related Stigma and Discrimination appear and the contexts in which they occur, there is need to understand how they interact with pre-existing Stigma and Discrimination associated with sexuality, gender, race, and poverty among other things. It is essential to also consider that while Stigma and Discrimination are exerted on the individual by the outside world (family, community, workplace etc), one can experience self-stigma as a result of how they feel, and fears that they have which can be real or imagined. As such, some of the recommendations from this study include the following actions to address HIV related Stigma and Discrimination:

- The starting point will be to ensure that the study findings are disseminated to relevant Government departments, The National AIDS Council, Donor Organisations, International and Local CSOs involved in HIV programming, and the PLHIV through their organised structures (the Support Groups) and to the general public in Zimbabwe.

- Continuously raise awareness on the need for people to know their HIV status, and to also engage in community mobilisation programmes through community dialogues, sensitisation meetings and the use of edutainment (poetry, drama, music, sports etc.) to impart key messages that discourage HIV related stigma.
- It is also important to engage in targeted interventions to address various sources of stigma especially with regards to key populations who suffer double stigma as a result of either being sex workers, prison inmates, people with disabilities or men having sex with men who are living with HIV. It may be necessary to raise awareness at all levels starting from Government and Parliament levels and to the person in the street that PLHIV, despite their social situation (for example, being a sex worker) still have a right to live and to access services equitably.
- Promote and encourage disclosure of HIV status to spouse/partner and within families to foster forward planning.
- Lobby for health strengthening systems which increases reach and availability of required services such as ART, VCT and PMTCT among others to the remotest parts of the country.
- Educate and develop the capacity of health service providers to provide health services without discriminating against anyone on the basis of their HIV status, and provide the services equitably regardless of whether an individual is a sex worker or is LGBTI given that the laws of the country through the Public Health Act allows for the provision of services without discrimination.
- There is need to promote workplace stigma reduction efforts through the development and implementation of HIV-Stigma free work policies, developing the capacity of managers, supervisors, workplace peer educators and counsellors to provide accurate and adequate HIV information to their peers in the workplace.
- Nationally, it is important that the Government of Zimbabwe relooks at the labour laws and recruitment procedures which require applicants to get tested for HIV first, after which they may be discriminated against in terms of getting the job.
- The HIV epidemic has transformed, and it is important that at a national level, players such as the National AIDS Council, the Zimbabwe National Network of People Living with HIV, The Zimbabwe AIDS Network, among others, transform their responses to focus on availability, quality, and accessibility of services among other things. On the same note, it may be useful to consider supporting SRH and HIV linkages including integrating SRH issues for PLHIV into HIV programmes.
- The CSOs (NGOs and FBOs) and Networks involved in HIV programming need to organise themselves and articulate their issues with one voice, especially if they are going to influence national policy. PLHIV who are members of Support Groups should be organised as well so as to raise critical policy issues, which seek to protect the interests of PLHIV.
- The support group model has proven to be very useful in providing emotional support, HIV information and services to PLHIV. As such, it is key to continuously develop the capacity of the support groups, faith based organisations and other community based organisations to provide adequate counselling and other services.
- There is need to assess the role of players such as NAC, ZNNP, ZAN among others in reducing HIV related stigma and discrimination as well as assess how effective NAC's Meaningful Involvement of PLHIV (MIPA) Programme has been in reducing HIV related stigma and how it has contributed to the empowerment of PLHIV.
- Evaluate the effectiveness of HIV in the Workplace Programmes that have been implemented by various players in the country.
- Include HIV related stigma and discrimination indicators as part of the National HIV Response M and E systems to monitor and evaluate progress over time.

- Females appear to be experiencing more stigma and discrimination compared to their male counterparts, and as such, there is need to integrate gender equity and equality issues in HIV programming, especially with a focus on reducing stigma and discrimination.
- It is worthwhile for those involved in HIV programming to consider separating enacted and self-stigma. While there are many programs that focus on enacted stigma, there are few programs that have been put in place to address issues of self-stigma, and one such program in the Inquiry Based Stress Reduction (IBSR) Program which has already been piloted in Zimbabwe by Trocaire.

Conclusion

Overall, the study suggests that while HIV programming in Zimbabwe has focused on HIV Prevention, Treatment Care and Support, there is still a gap with regards to HIV related stigma and discrimination. PLHIV still experience different forms of stigma and discrimination which include being gossiped about, exclusion from social, religious and family activities, verbal and physical abuse among other things. HIV related stigma is reported to be still evident in the workplace, educational institutions, and also in the health institutions. However, there is evidence that some PLHIV suffer from self-stigma, which has affected the decisions and choices that they make. While HIV stigma and discrimination still needs to be addressed, it is commendable that Zimbabwe has made strides in terms of provision of services such as VCT, ART, PMTCT as evidenced by the number of people who reported to be on treatment, and also to have received pre and post-test counselling. In addressing HIV related stigma and discrimination, those responsible for HIV programming should consider addressing self-stigma, community mobilisation against stigma, lobbying for equitable health service provision, and lastly transforming the national response and working together to ensure that HIV related services are accessible, available and of an optimum required quality.

CHAPTER 1: INTRODUCTION

1.1 Background on HIV-related Stigma and discrimination

The existence of stigma within society has been the subject of empirical investigation for decades, especially in the disciplines of psychology and sociology. The impact of being stigmatized on an individual's psycho-social wellbeing and self-perception and behaviour have been well documented in the literature. Stigma occurs when an individual with a particular attribute (e.g. disability, illness, behavioural tendency) is deeply shunned, resented and even rejected by peers and/or members of the society simply because of having the attribute. As far back as the 1960s, social scientists recognized that stigma negatively affects an individual's identity¹.

Stigma is closely related to social stereotyping, a phenomenon that has also been widely investigated in the social sciences. When society categorizes individuals into certain groups, the group is often subjected to status loss and discrimination.² The stigmatized individuals are thus ostracized, devalued, rejected, scorned and/or shunned. Besides being discriminated, they may also at times experience insults, attacks and may even be murdered. Those who perceive themselves to be members of a stigmatized group, whether it is obvious to those around them or not, often experience psychological distress and many view themselves disdainfully.³

As noted at the 2012 International Conference on Stigma at the Howard University College of Medicine:

"...when stigma is associated with a medical condition or disability, it prevents individuals from seeking evaluation and treatment, disclosing the diagnosis to the people most likely to provide support and in following treatment guidelines. While there are many illnesses such as leprosy that have been severely stigmatized in the past, it is generally agreed that HIV/AIDS is the most stigmatised medical condition in the history of modernity. While society elevates the status of those receiving treatment for some conditions such as cancer or serious injuries as heroes, those who have acquired HIV are subjected to layer upon layers of stigma with assumptions that these individuals are deserving of punishment for their "assumed behaviour" that led them to get HIV and they are often shunned..."⁴

HIV and AIDS stigma and discrimination exists worldwide, although they manifest themselves differently across countries, communities, religious groups and individuals. They occur alongside other forms of stigma and discrimination, such as racism, stigma based on physical appearance, homophobia or misogyny and can be directed towards those involved in what are considered socially unacceptable activities such as prostitution or drug use.⁵

¹ Erving Goffman (1963). *Stigma: Notes on the Management of Spoiled Identity*. Prentice-Hall.

² Jacoby A, Snape D, Baker GA. (2005), "Epilepsy and Social Identity: the Stigma of a Chronic Neurological Disorder", *Lancet Neurology* 4 (3): 171–8, doi:10.1016/s1474-4422(05)70020-x, PMID 15721827

³ Ibid.

⁴ <http://www.whocanyoutell.org/wp-content/uploads/2013/03/FULLSTIGMAPROGRAMBOOK2013.pdf>

⁵ UNAIDS (2008) 'Report on the global AIDS epidemic'

The International Centre for Research on Women (a UNAIDS affiliated institution) has pointed out that stigma not only makes it more difficult for people trying to come to terms with HIV and manage their illness at a personal level, but it also interferes with attempts to fight the HIV and AIDS epidemic as a whole. On a national level, the stigma associated with HIV can deter governments from taking fast, effective action against the epidemic, whilst on a personal level it can make individuals reluctant to access HIV testing, treatment and care.⁶

In a 2008 article titled "*The stigma factor*", the UN Secretary-General Ban Ki Moon said:

*"...stigma remains the single most important barrier to public action. It is a main reason why too many people are afraid to see a doctor to determine whether they have the disease, or to seek treatment if so. It helps make AIDS the silent killer, because people fear the social disgrace of speaking about it, or taking easily available precautions. Stigma is a chief reason why the AIDS epidemic continues to devastate societies around the world..."*⁷

AIDS-related stigma has had a profound effect on the epidemic's course. The WHO cites that "... fear of stigma and discrimination as the main reason why people are reluctant to be tested, to disclose their HIV status or to take **antiretroviral drugs...**"⁸ One study found that participants who reported high levels of stigma were more than four times more likely to report poor access to care. These factors all contribute to the expansion of the epidemic (as a reluctance to determine HIV status or to discuss or practice safe sex means that people are more likely to infect others) and a higher number of AIDS-related deaths. An unwillingness to take an **HIV test** means that more people are diagnosed late, when the virus has already progressed to AIDS, making treatment less effective and causing early death.⁹

AIDS-related stigma is not static. It changes over time as infection levels, knowledge of the disease and treatment availability vary. In 2003, when launching a major campaign to scale-up treatment in the developing world, the World Health Organization (WHO) made an assertion that:

*"...as HIV/AIDS becomes a disease that can be both prevented and treated, attitudes will change, and denial, stigma and discrimination will rapidly be reduced..."*¹⁰

Social stigma plays a significant role in the state of HIV and AIDS infection in Africa. In HIV/AIDS-stigmatising Sub Saharan African communities, the suspicion of one's status by others is also applicable to individuals who are not HIV positive, but who may wish to utilize healthcare services for preventative purposes. This group of individuals, under fear of

⁶ ICRW (2005), ' HIV-related stigma across contexts: common at its core'

⁷ Ban Ki-moon op-ed (2008, 6th August), '[The stigma factor](http://www.avert.org/hiv-aids-stigma-and-discrimination.htm#sthash.0xCAFbPy.dpuf)', The Washington Times - See more at: <http://www.avert.org/hiv-aids-stigma-and-discrimination.htm#sthash.0xCAFbPy.dpuf>

⁸ The WHO Strategy (2003) 'Treating 3 Million by 2005: Making it Happen' - See more at: <http://www.avert.org/hiv-aids-stigma-and-discrimination.htm#sthash.0xCAFbPy.dpuf>

⁹ Sayles J et al (2009, October), ' The Association of Stigma with Self-Reported Access to Medical Care and Antiretroviral Therapy Adherence in Persons Living with HIV/AIDS' *Journal of General Internal Medicine* 24(10)

suspicion, may avoid being mistakenly identified as stigmatized by simply avoiding HIV and AIDS Reproductive Health Service utilization ¹¹

At the individual level, persons living with HIV/AIDS in Sub-Saharan Africa likely to conceal their stigmatized identities as much as possible in order to gain the rewards associated with having a 'normal' identity. The rewards of being considered "normal" in the context of high-HIV-prevalence Sub-Saharan Africa are varied and great. Such rewards, for which there is empirical support, include perceived sexual freedom, avoidance of discrimination, avoidance of community or family rejection, avoidance of losing one's job or residence, and avoidance of losing one's sexual partners. Other potential rewards of being considered normal include avoidance of being associated with promiscuity or prostitution, avoidance of emotional, social and physical isolation and avoidance of being blamed for others' illness¹².

The result of stigma associated with HIV and AIDS is discrimination which manifests in violation of human rights of those thought to be, or who are affected or infected by HIV and AIDS. The violation of rights increases the negative impact of the epidemic and serves to perpetuate its spread. HIV and AIDS related stigma is manifested in a wide range of community contexts including the family and immediate community, workplace, health services, religion and the media.

Stigma in the family context

Existing gender inequalities in southern Africa have contributed towards blaming of women for bringing HIV to their husbands and families. HIV positive women often suffer discrimination as a result of their diagnosis, either from their partners or from their in-laws if they are widows. The changes in HIV positive women's lives are shaped by the unequal gender relations, poverty, and the physical effects of the virus. Economic challenges for HIV positive women are increased by violation of their human rights, fuelled by cultural practices such as wife-inheritance. Economic dependency on men, sexual relations and cultural dictates binding most HIV positive southern African women, increase the stigma they face in the community. Consequences of gender based HIV and AIDS related stigma include failure of disclosure leading to poor health seeking behaviour by women. Many women fear violence, rejection and abandonment which could lead to socio-economic insecurity for them and their children, if they disclose their positive status to their partner or families. ¹³

Stigma in the work context

In many instances, HIV-positive individuals fear stigmatisation by colleagues and employers. Many employers and fellow employees discriminate against workers suspected of being (or confirmed to be) HIV positive.

¹¹ WHO (2011) '[Global HIV/AIDS Response: Epidemic update and health sector progress towards Universal Access: Progress report 2011](http://www.avert.org/hiv-aids-stigma-and-discrimination.htm#sthash.0xCAFbPy.dpuf)' - See more at: <http://www.avert.org/hiv-aids-stigma-and-discrimination.htm#sthash.0xCAFbPy.dpuf>

¹² A., Van Niekerk A., and Loretta M. Kopelman. Ethics & AIDS in Africa: The Challenge to Our Thinking. Walnut Creek, CA: Left Coast, 2005

¹³ Positive Women: Voices and Choices- Zimbabwe Report, by Rayah Feldman, Joe Manchester and Caroline Maposhere, June 2002

Some reasons for this behaviour include:

- Ignorance on facts around HIV transmission and progression of the disease
- Fear by employers or superiors, of reduction in productivity and profits.
- Fear of absenteeism
- Fear by employers or superiors, of medical aid, funeral and other care costs.
- Fear of stigmatisation of the organisation in the advent that clients get to know workers are HIV positive.

It is common for workers not to be recruited, denied promotion, benefits and staff development opportunities, on the basis of their HIV status. A consequence of this stigma is an increase in the financial burdens faced by most infected or affected families, as more breadwinners are prematurely laid off work. This compromises family access to healthcare, nutrition, shelter and education, making their intentions to live positively difficult. Another consequence of this form of stigma is the premature loss of productivity that the workplace faces with premature loss of skilled labour as workers leave or are dismissed from work, or have reduced self-esteem and concentration at work. The world of work offers a vast and valuable opportunity for addressing HIV as it is a place where people spend the majority of their time interacting with others.¹⁴

Stigma in the community.

In order to get HIV and AIDS into the public agenda, it is important for persons living with HIV/AIDS to speak publicly, however the climate of stigma and discrimination surrounding HIV and AIDS can make public acknowledgement of one's HIV status difficult and dangerous, especially for members of vulnerable populations including women, children, the disabled, prisoners, migrants, commercial sex workers and others.

Stigma within a family and from the community is the most subtle and devastating form of stigma and most difficult to address. Families and communities, are deeply intertwined in the African context and need to be supported in preventing stigma and discrimination. This support will facilitate their natural caring role and promote self-esteem of PLHIV and their careers. The role of media, celebrities and public opinion leaders in mobilising masses to disregard HIV and AIDS as a reason for discrimination needs urgent exploration.¹⁵

Stigma in the health system context.

Breach of confidentiality, direct or indirect verbal insults and denial of the right to quality health care are among the most common practices which tend to result from HIV and AIDS related stigma displayed by health workers. Some reasons for this behaviour may include lack of knowledge and skills around the epidemic, fear of infection and the health worker's

¹⁴ Strategies for Hope No. 8: Work Against AIDS, Workplace-based AIDS Initiatives in Zimbabwe, G.Williams and Sunanda Ray, Published by ActionAid and AMREF- December 1993

¹⁵ HIV/AIDS and Human Rights: Stories from the Frontlines, International Council of AIDS Service Organisations (ICASO), June 1999

own vulnerability to HIV infection, work overload and feelings of helplessness in handling clients' needs. This poses a serious threat to HIV and AIDS prevention, care and support. Efforts made to prevent partner infection become less effective, as few individuals choose to disclose their status to the health system fearing pending stigma and discrimination¹⁶

Stigma in the religious context.

Contributing factors to stigma in the religious arena include association of the epidemic with sexual promiscuity and sin. Issues around birth control, condom use and frank discussion on sexuality with young people are often viewed as sinful and immoral. Women and youth, two vulnerable populations in the epidemic, are often not accepted as equal members of the faith community, and this may influence the HIV and AIDS related stigma and prejudice they face from the religious sector. Consequences of stigmatisation from this sector are probably quite challenging, as usual, religion is the last thing a person clings to in times of great difficulty and suffering, when both hope and help seem to be far away. The religious sector has far-reaching influence and carries a responsibility to reduce stigma and discrimination by promoting care, love, compassion and support for individuals and communities who are both infected or affected by HIV.¹⁷

In efforts to combat religion-based HIV and AIDS related stigma and discrimination, various best practices can be drawn from within the African continent. The Anglican Church has made special efforts in Uganda to ensure that people living with HIV are welcomed into the church. In Nigeria, the same church utilises up-to-date information on HIV and AIDS to counter local myths and profiteering, and in Burundi the church includes HIV and AIDS education as part of its post-conflict resettlement activities. In Zimbabwe, the same church has various community based interventions which it carries out through the ARDeZ arm of the church. These and other noteworthy examples offer a sense of confidence that the religious sector can offer effective forms of care and support for those infected and affected by the epidemic.¹⁸

Stigma in the media

The role of the media in bringing about or influencing positive change in today's society is widely acknowledged. In view of the current HIV and AIDS pandemic, the media is an extremely powerful and useful channel for raising awareness and working towards the elimination of stigma and discrimination. What and how the media chooses to report on can translate into positive change in society's appreciation and understanding of the pandemic. Focusing on issues that bring hope, positive healthy living and successful coping strategies can contribute in fostering an enabling environment for PLHIV and the support they can readily obtain from society.¹⁹

Children and HIV and AIDS Stigma

¹⁶ Accelerating Action against AIDS in Africa, UNAIDS, Geneva, 2003

¹⁷ HIV/AIDS and Human Rights: Stories from the Frontlines, International Council of AIDS Service Organisations (ICASO), June 1999

¹⁸ A Broken Landscape: HIV and AIDS in Africa, by Gideon Mendel, Published by ActionAid

¹⁹ http://www.safaid.net/files/The_Reality,_Stigma_and_Discrimination.pdf

Research has indicated that one of the most common forms of stigma experienced by children affected by HIV and AIDS is teasing and social isolation by peers. This suggests that children adopt the generally accepted societal attitudes towards HIV and AIDS at an early age and should be included in efforts to reduce HIV and AIDS related stigma and discrimination.²⁰

Gays, Lesbians, Bisexuals and Transgendered people and HIV and AIDS Stigma

It is very difficult for gays, lesbians, bisexuals and transgender people to be open about their sexuality in southern Africa due to stigma and discrimination, which normally faces them upon disclosure of their sexual orientation. Their vulnerability to HIV infection is thus enhanced as HIV and AIDS responses rarely address their sexual needs and concerns. Lack of access to information, along with discrimination in the provision of basic services puts homosexuals, bisexuals and transgender people at particular risk of contracting HIV and facing the double dilemma of stigma and discrimination by society. As these vulnerable groups continue to be prejudiced, transmission of HIV among them is driven underground and will continue uncontrolled. Having to deal with a double disclosure (of being homosexual and HIV positive) may drive many to commit suicide or to spend their final days in misery and much emotional and physical pain²¹

Self-Stigma

Self-stigma occurs mostly among people who are symptomatic; it is a situation whereby a person feels that people are looking at her/him or behaving differently towards them, and that they can actually see that she/he is positive. The other factor is that persons living with HIV and AIDS who take antiretroviral drugs assume that they shall be stigmatised if seen taking many pills and believe that someone will actually wonder why they are taking so much medication and label them as HIV infected. Self-stigma may also be a product of a person's low self-esteem.

Self-stigma hinders HIV positive people from continuing with or designing new plans for their future. Many drop out of their social circles; sacrifice their education and sometimes their professional pursuits. The resultant change in lifestyle brought about by self-stigmatisation offers other people opportunities to stigmatise and discriminate against HIV positive persons. ²² Self-stigma also affects the health and nutrition of PLHIV as this causes stress and depression which have a significant impact on the appetite and ultimate nutrition intake.

A Baseline Survey for an HIV Programme conducted in March 2011 by Trocaire in Zimbabwe indicated that there was a need to separate enacted stigma and self-stigma. During the study, a self-stigmatization score was developed in order to gauge respondents'

²⁰ Investing in the Future: Psychosocial Support for Children Affected by HIV/AIDS Case Study Published by UNAIDS, July 2001

²¹ **MORE THAN A NAME: STATE-SPONSORED HOMOPHOBIA AND ITS CONSEQUENCES IN SOUTHERN AFRICA, 2003; HUMAN RIGHTS WATCH, INTERNATIONAL GAY AND LESBIAN HUMAN RIGHTS COMMISSION. NEW YORK, HUMAN RIGHTS WATCH, 2003**

²² Strategies for Hope No. 8: Work Against AIDS, Workplace-based AIDS Initiatives in Zimbabwe, G.Williams and Sunanda Ray, Published by ActionAid and AMREF- December 1993

overall feelings about themselves in the face of being positive. There were 10 questions to be scored with highest score possible being 10 which would indicate a respondent feeling very despondent and in great need of counselling. Overall just over half of the respondents scored a total of 0 reflecting good feelings about themselves whilst one third scored between 1 and 3 and the remainder scored 4 or more, indicating some serious self-guilt in 4 or more of the situations. Rural urban differences were minimal whilst differences between age groups and also between sexes were noticeably different. Females and those in the middle age group were much more likely to harbour bad feelings about themselves. Those with some background training in HIV were slightly less likely to have many bad feelings about themselves. Members and non-members of support groups scored equally. Thus, self-stigma and enacted stigma may need to be separated. Self-stigma can be tackled directly by involvement in support groups and accessing the training and support they offer. Enacted stigma is about disclosure to a wider group and behaviour change in the wider group²³.

1.2 Country Context

1.2.1 Overview

With only 5 per cent of the world's population, Eastern and Southern Africa is home to half the world's population living with HIV. The Southern Africa sub-region, in particular, experiences the most severe HIV epidemics in the world. Nine countries - Botswana, Lesotho, Malawi, Mozambique, Namibia, South Africa, Swaziland, Zambia and Zimbabwe - have adult HIV prevalence rates of over 10 per cent.²⁴

Zimbabwe has a total population of 13 million, with a population growth of 1.1%.²⁵ Zimbabwe has a generalized heterosexually driven HIV epidemic with adult prevalence of 15%²⁶ and an incidence of 0.98%²⁷. The epidemic looks fairly homogenous with similar HIV prevalence levels across the ten provinces. However there are hot spots of HIV which are Border towns, mining areas, growth points and resettlement farms. The HIV prevalence is slightly higher in urban areas than in rural areas. HIV prevalence in 15-24 age group women is 1.5 times higher than in men of the same age.

The decline in HIV prevalence was projected to have started in the late 1990's according to the 2012 version of Epidemic Projection Package spectrum (Figure 1). The prevalence peaked in 1997 at 26.48% (24.96 – 27.77%) and started declining thereafter.

²³ Trócaire Zimbabwe HIV Programme: Baseline Survey Report March 2011

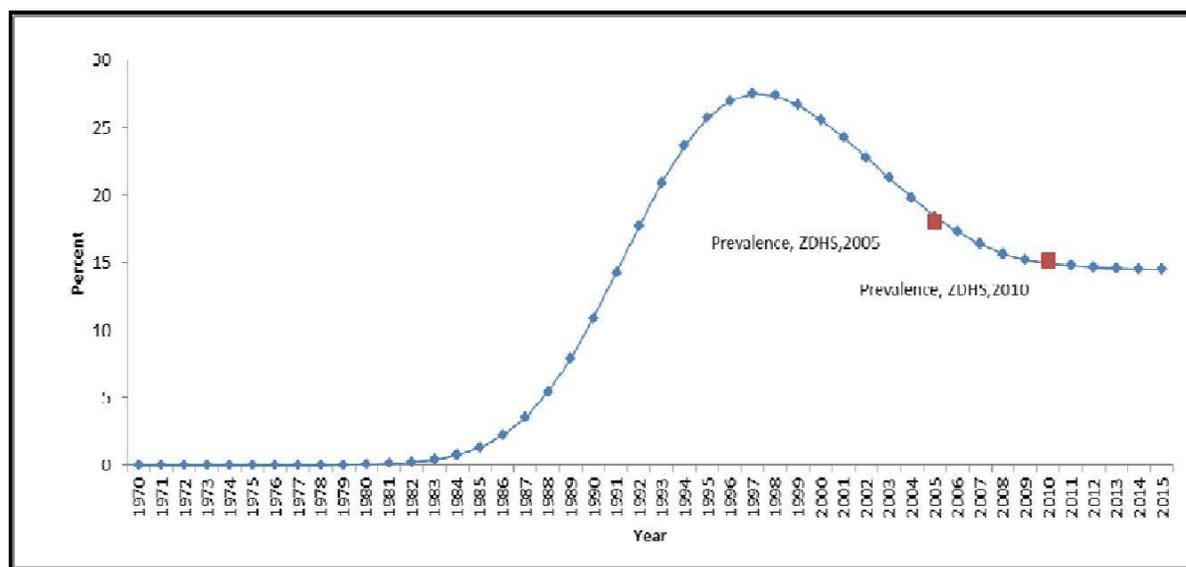
²⁴ http://www.unicef.org/esaro/5482_HIV_AIDS.html

²⁵ Zimbabwe Population Census Report 2012.

²⁶ Zimbabwe Demographic Health Survey Report 2010/11

²⁷ Zimbabwe National HIV and AIDS Estimates Report 2013

Figure 1: Trends in Adult (15+) HIV Prevalence, Zimbabwe 1970-2015



Source: National HIV and AIDS Estimates Report 2012

There was a sharp drop in HIV incidence from about 5.5% in adults in 1992 to about 0.98% in 2013. This decline in new infections is attributed to gains from positive behaviour change and high ART coverage. New HIV infections in children up to 15 years of age have been declining due to overall lower levels of both HIV infection in women at child bearing age and mother-to-child transmission interventions.²⁸

1.2.2 National Response

Policy and Programmatic Response

Zimbabwe has over the last 25 years developed a policy environment for HIV prevention culminating in a multi-sectoral approach led by the National AIDS Council. In 1999, the National Policy on HIV and AIDS was adopted, followed by creation of the National AIDS Council through an Act of Parliament. There is a large number of policy instruments relevant to HIV prevention at national and sectoral level.²⁹

The national response has been guided by the following policies and strategic documents in Zimbabwe:

1. National AIDS Council Act 1999,
2. Criminal Law Codification Reform Act (2006)
3. Statutory Instrument 202 of 98
4. Income Tax Act,
5. National HIV Policy 1999,

²⁸http://www.unaids.org/en/dataanalysis/knowyourresponse/countryprogressreports/2014countries/ZWE_narrative_report_2014.pdf

²⁹ Global AIDS Response Country Progress Report for Zimbabwe 2014, p.5

6. National Health Policy in the Zimbabwe Agenda for Sustainable Socio Economic Transformation(ZIMASSET),
7. Zimbabwe National HIV and AIDS Strategic Plan (ZNASP 2011 – 2015),
8. National Health Strategy (2011 – 2015).³⁰

The government facilitated the review of the National HIV and AIDS strategy in order to align it with international commitments. Zimbabwe has adopted the investment case model to implement the prioritised interventions that contribute to specific impact results.³¹

Several structures at national and decentralized levels have a mandate to coordinate the complex multi-sectoral HIV response. There is acknowledgement of NAC as the overall coordinating body while the Zimbabwe AIDS Network coordinates the civil society response. Also of importance is the role of faith and community based networks and organizations.

The Government of Zimbabwe continues to collect the AIDS Levy which is 3 % of payee and corporate tax. The tax is collected by the Zimbabwe Revenue Authority and is directly remitted on a monthly basis to the National AIDS Council. The AIDS levy is the major contributor of domestic funding for the national response. The government continues to receive external support from the Global Fund, US Government, Department for International Development (DfiD) and other international partners³².

National Response: Priority Intervention Areas

The scope of the national response as articulated and prioritised in the ZNASP II for the period 2011 to 2015 is detailed in table 1 below.³³

³⁰ *Ibid* p.5-6

³¹ *Ibid* p.6

³² *Ibid.* p.7

³³ The Zimbabwe National Aids Strategic Plan 2011 – 2015, p.25

Table 1: Prioritised Interventions for ZNASP II (2011-2015)

Prevention	Treatment, Care and Support	Coordination, Management and Systems Strengthening
Social and Behaviour Change Communication	Antiretroviral Therapy (ART)	Enabling Policy and Legal Environment
Condoms – promotion and distribution	Nutrition	Coordination and Management of the National response
Male Circumcision	Community Home Based Care (CHBC)	Mainstreaming/Integration of HIV and AIDS
PMTCT	Support for Orphans and Vulnerable Children (OVC)	Systems Strengthening
HIV testing and counselling (to enhance preventions and treatment)		Strategic Information Management
Treatment and Control of Sexually Transmitted Infections		Sustainable Financing and Resource Mobilisation
Blood Safety		
Provision of Post Exposure Prophylaxis		

Source: Zimbabwe National HIV/AIDS Strategic Plan II (2011 – 2015)

1.3 Existing Research on Stigma and Discrimination in Zimbabwe

Whilst there has been much research conducted on HIV and AIDS in the Zimbabwean context, work that focuses on HIV related Stigma and Discrimination is limited. The existing body of research focuses on aspects of HIV-related Stigma and Discrimination in specific communities only. The Stigma Index Research bridges this gap by providing a national perspective on the prevalence of HIV related stigma and discrimination as experienced by PLHIV.^{34,35}

1.4 About ZNPP+ and Project Steering Committee

Zimbabwe National Network of People Living with HIV (ZNNP+) was founded in 1992 and officially registered as a Non-Governmental Organization in 1999. ZNNP+ is a national umbrella body that represents and coordinates the interests and activities of support groups of People Living with HIV throughout Zimbabwe. The organization promotes the empowerment of PLHIV through skills development, counselling, education and by lobbying for the rights of PLHIV. The organization has a membership of more than 5000 support groups.

In May 2012, the Stigma Index Research Advisory Board was formed with a mandate to facilitate the carrying out of a Stigma Index Research in Zimbabwe. The Advisory board included representatives from:

- National AIDS Council NAC (Chair),
- Zimbabwe AIDS Network (ZAN),
- Zimbabwe National Network of People Living with HIV (ZNNP+) Secretariat,

³⁴ Nhamo, M. (2011) *The Role of Churches in Tackling HIV Stigma in Eastern Zimbabwe*. London School of Economics and Political Science.

³⁵ Nhamo – Murire, M, Campbell, C & Gregson, S. (2013) *Community Group Membership & Stigmatising Attitudes Towards People Living with HIV in eastern Zimbabwe*. Journal of Community Health (2014) 39: 72 – 82.

- The Joint United Nations Programme on HIV/AIDS (UNAIDS),
- Zimbabwe Council of Churches (ZCC),
- Southern Africa HIV and AIDS Information Dissemination Services (SAfAIDS),
- Union for the Development of Apostolic Churches in Zimbabwe Africa (UDACIZA),
- Zimbabwe HIV and AIDS Activists' Union (ZHAAU),
- Padare,
- Anglican Relief and Development in *Zimbabwe* (ARDeZ),
- Biomedical Research and Training Institute (BRTI),
- Students and Youths Working on reproductive Health Action Team (SAYWHAT),
- United Nations Population Fund (UNFPA),
- Trócaire,
- Tear Fund,
- National Council of Disabled Persons of *Zimbabwe* (NCDPZ),
- The International Community of Women Living with HIV/AIDS (ICW) – Zimbabwe (Co-Chair),
- Gays and Lesbians Association of Zimbabwe (GALZ), and
- Evangelical Fellowship Zimbabwe (EFZ).

In February 2013, the Advisory Board commissioned Impact Research International Zimbabwe (IRiZ) to carry out the Stigma Index for Zimbabwe study. Representatives from the above-mentioned organisations, together with IRiZ carried out the study, the findings of which are presented in this report.

1.5 Objectives of the study

The objectives of the Stigma Index for Zimbabwe were as follows:

- (i) To understand the nature of and rates of ***HIV-related stigma*** and discrimination at a national scale,
- (ii) To ***increase the evidence base*** for HIV related policies and programmes,
- (iii) To ***ensure that Meaningful Involvement of People Living with AIDS (MIPA)*** is enshrined in local, regional and national responses to HIV in the country.

CHAPTER 2: METHODOLOGY

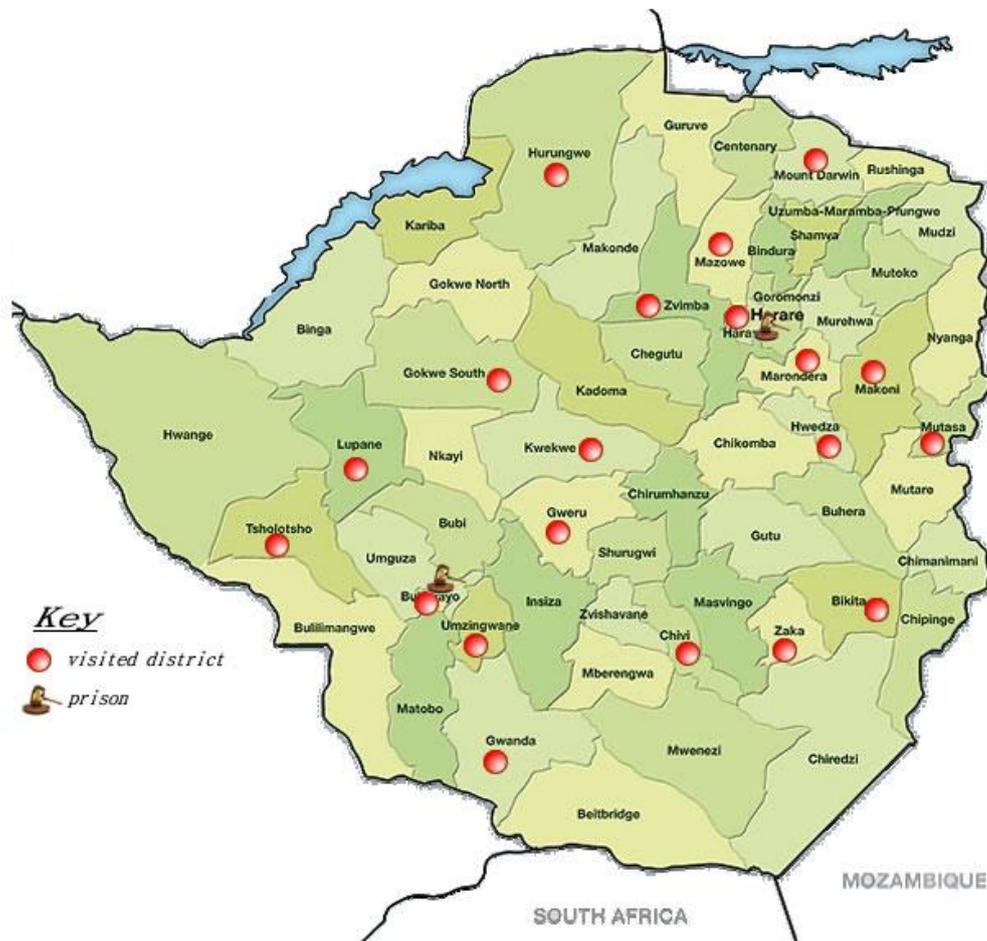
2.1 Study Design

The study involved utilization of both quantitative and qualitative data collection methods. A cross sectional survey was conducted through a questionnaire that was administered among PLHIV. The questionnaire that was used is the People living with HIV Stigma Index which was developed by and for people living with HIV to gather quantitative data. The tool was developed by:

- the Global Network of People Living with HIV/AIDS (GNP+),
- the International Community of Women Living with HIV/AIDS (ICW)
- the International Planned Parenthood Federation (IPPF)
- the Joint United Nations Programme on HIV/AIDS (UNAIDS)

In addition, case studies, identified during the data collection process were documented. Case Studies complimented the quantitative data and served to bring to life real-life experiences of individuals who had both positive and negative experiences to share. In addition, additional data were collected through in-depth interviews with key informants and national, provincial and district levels. The study was implemented in all the 10 provinces, and 3 districts were selected from each province. The map below shows the districts which were covered during the research. **(See Appendix K for the Table with provinces and districts covered)**

Figure 2: Study Districts and Areas



2.2 Study Tools

Survey Questionnaire

The People Living with HIV Stigma Index questionnaire (refer to separate attachment Document 1) was used as this tool was developed to measure HIV related stigma and discrimination, the impact of interventions, and the documentation of the well-being of people living with HIV over time. The aim was to collect data that was standard and comparable with the internationally accepted standard format for HIV related Stigma Index Research. Given this background, the questionnaire was deemed to be appropriate. The tool allowed for an exploration of the following key areas:

- i. causes of stigma and discrimination;*
- ii. access to work and services;*
- iii. internal stigma;*
- iv. awareness of rights, laws and policies;*
- v. effecting change;*
- vi. disclosure and confidentiality,*
- vii. treatment; having children;*
- viii. Overcoming stigma.*

The questions respondents asked to respond to the questions based on their experiences in the 12 months preceding the study, and the findings provided a snapshot for that moment in time.

Focus Group Discussions

A guide was developed for use during focus group discussions. The male and female guides were identical as the constructs being explored were the same (see Appendix A). Participants were asked:

- to share their understanding of the concept of “HIV related stigma and discrimination”. Based on this understanding, they were asked if they felt PLHIV experienced HIV related stigma and discrimination. If they confirmed that PLHIV experienced stigma and discrimination, participants were asked which groups of PLHIV were most vulnerable to this stigma.
- to share which forms of stigma and discrimination were prevalent in their areas and if they had been exposed to any information on stigma and discrimination from any sources (such health facilities or other institutions)
- if they thought PLHIV in their community were comfortable disclosing their status and if there were support structures for PLHIV who became victims of stigma and discrimination in their community
- if they were aware of any national policies and/or strategies that aimed at reduction of HIV related Stigma and discrimination and if they had any recommendations thereof.

In – Depth Interviews with National Level Key Stakeholders

Three versions of the Key Informant Interview guide (see Appendix B) were developed for use with District level, Community Level and National level key informants respectively. Whilst the questions asked were of a similar nature, they were fine tuned to elicit the appropriate information from the three different key informants. Pertinent issues explored in these guides were as follows:

- Determining the understanding of key informants as related to the concept of HIV related Stigma and Discrimination.
- The types of key populations key informants were involved with and the types of stigma experienced by PLHIV in their area. Furthermore they were asked how they responded to cases of HIV related stigma and discrimination that were brought to them.
- They were asked of the relevance of national HIV policies and strategies and asked to give recommendations if they had any.

Case Study Guide

This was an optional part of the process and it was not essential for the construction of the People Living with HIV Stigma Index, but it was considered helpful in providing illustrations of the problems and challenges encountered by people living with HIV on a daily basis, and how they positively responded to them. If the interviewer considered a particular interviewee as a possible candidate for a case study, they invited the candidate for a second interview. The idea behind this second interview was that if the interviewee appeared to be an important case, the interviewer would ask if they could return for a more in-depth qualitative interview and, if possible, agree on a time then and there. In this case, the interviewer ticked “Yes” in answer to Question 4 in the referrals and follow-up section on the front page and recorded the time and date in Question 5; otherwise, the interviewer would just tick “No” for Question 4. The interviewers were alerted on areas to be explored in greater depth in the case studies and which responses they ought to pay particular attention to in terms of identifying potential material for a follow-up case study.

This tool sought to further explore individual cases of PLHIV who had profound experiences of HIV related stigma and discrimination. Respondents were asked to:

- Give details regarding how long they had lived positively, if they had disclosed their status to anyone, if they had a support system in place, et cetera.
- Give details of the worst form of HIV related Stigma and Discrimination they had encountered and how they had dealt with it.

Appropriate probes were utilised throughout the Case Study Guide (See Appendix C)

Eight case studies in 3 provinces which are Masvingo (1), Mashonaland East (4) and Mashonaland West (3) were documented.

2.2.1 Translation of data collection tools

The data collection tools (which included the questionnaire, the FGD and IDI Guides and other accompanying documents) were translated into Shona and Ndebele by SAfAIDS and were reviewed during training and finalised by the IRI and ZNNP+ who participated at the training workshop. A considerable amount of time and effort was devoted to this exercise in order to ensure that the wording was conceptually correct in the local languages to ensure respondents understood each question.

2.3 Sampling Procedures

For the Questionnaire survey, a sample size of 1,768 was determined using the Probability Proportional to Size Cluster Sampling (Sample size formula in Appendix), which is a Multi stage sampling technique.

Stage 1 Cluster sampling

Our sampling frame consisted of PLHIV who were members of ZNNP+ and Church structures in all provinces in Zimbabwe. These groups were homogeneous, and we therefore clustered the target population into 10 clusters represented by the 10 provinces in Zimbabwe. (Clusters A- J are shown in Appendix D). Appendix E also shows the weighting which was done to come up with sample size (n) per province. The weighting considers the HIV prevalence rate (ZDHS 2010-2011) by province. The ZDHS prevalence rate is at population level and is not broken down by key populations at risk of HIV, who were people living with disabilities, commercial sex workers, prisoners, MSM, IDUs, etc. The sampling was designed to include these key populations..

Stage 2 Stratification by district

In each province, three districts were selected. The provincial sample size was divided by the number of districts, such that there was equal representation of respondents from each district in the province. The districts used in the sampling frame (see Appendix F) are those that were used in the 2012 Census by Zimbabwe National Statistics Agency (ZIMSTAT).

Stage 3 Sampling of Respondents

At this stage, with the help of ZNNP+ and Church groups representatives identified a ward in each district in which members of support groups affiliated to both ZNNP+ and church groups were sampled. At this level, an equal number of both male and female respondents was sampled. Also, adolescents aged 15-24 were specifically targeted such that they were half the total sample. The researchers then finally randomly sampled respondents from each district. These respondents were identified through the support groups which are affiliated to both ZNNP+ and Church groups.

Inclusion Criteria

The following criteria was used to determine eligibility:

1. confirmed HIV-positive status,
2. registered member of a registered support group
3. 18 years old or older,
4. Ability to communicate in Shona, Ndebele, or English; the main languages spoken in Zimbabwe
5. Consent to be part of the study

People below the age of 18 years were excluded because it was difficult to get consent from their parents and guardians. Besides, it was felt that participation by under-age respondents would pose some risks which could not be dealt with in the context of this study (emotional trauma, unknown long term effects on psychological wellbeing, etc.). Also, non-Zimbabweans were excluded from the study (e.g. transit populations passing through Zimbabwe to another country or temporarily visiting the country).

Stage 4 Sampling of Key Populations

Globally, Sex Workers (SWs), Men having Sex with Men (MSM), Intravenous Drug Users (IDUs), prisoners and people living with disabilities have been shown to be at disproportionate risk for HIV infection. Broadly speaking, the international HIV response has not adequately provided services that address the needs of these groups, and, as a result, the HIV epidemic continues to have an impact within these key populations. These 'key populations' form part of the general population, have many overlapping needs and concerns and, while they are not epidemiologically

separated, they do have a unique impact on both concentrated and generalised HIV epidemics and most importantly their inclusion in HIV interventions can improve the overall impact of HIV responses. We were aware that these populations are still facing discrimination, including discrimination in health care, denial of their existence by some states, criminal sanctions and social exclusion in others. We realised that these populations may be left out because they are not easily forthcoming.³⁶

This research sought to include these key populations and document their experiences with regards to HIV related stigma, in the Zimbabwean context. In order to acquire the samples, the researchers were assisted by following organisations:

- i. Government departments,
- ii. Civil Society Organisations,
- iii. Faith Based Organisations,
- iv. Centre for Sexual Health, HIV/AIDS Research (CeSHHAR),
- v. Gays and Lesbians Association of Zimbabwe (GALZ),
- vi. Zimbabwe Prison and Correctional Services (ZPCS) and
- vii. National Council of Disabled People Zimbabwe NCDPZ.³⁷

Generally, participants from these key populations were difficult to identify. Thus, Respondent Driven Sampling (RDS) was used, where the first participants in these key population groups to be interviewed were identified through an organisation working with the group and then the interviewees identified other potential participants who could be interviewed by the researchers.

Sampling for the Focus Group Discussions

Two Focus Group Discussions in one purposively selected district per province were conducted. Two FGD guides, one for use with males and the other for use with females were developed.

2.4 Recruitment and Training of Data Collectors

Ten supervisors (one for each province in Zimbabwe) and 30 research assistants were recruited by the researchers and a committee of the advisory board which was tasked with this responsibility. The selection team was composed of National Aids Council, ZNNP+ and District Administrators. Of all the fieldworkers, 40% were field workers from key populations and the remainder were identified through the churches and other groups. to the selection team ensured that there was the required mix of male and female fieldworkers of different age groups who spoke English and the various Shona and Ndebele dialects. This was critical as we sought to ensure that the field team was appropriate for purposes of this study.

A training of trainers (TOT) workshop for the 10 supervisors was facilitated by the researchers. During this training, available members of the Stigma Index Advisory Committee were invited to attend. Training of Research Assistants was then conducted by the trained provincial supervisors. The trainings were simultaneously conducted in two areas: Northern Region and Southern region. The interviewers were trained to carry out the interviews using the People Living with HIV Stigma Index questionnaire, the in-depth interview (IDI) Guide and the FGD Guide. They were

³⁶ Best Practices Guidance in conducting HIV Research with gay and bisexual men, other men who have sex with men (MSM), in rights constrained environments *Developed in partnership by: amfAR, the Foundation for AIDS Research; Johns Hopkins University – Center for Public Health and Human Rights (JHU-CPHHR); International AIDS Vaccine Initiative (IAVI); and the United Nations Development Program (UNDP).*

also trained on interviewing techniques, facilitating focus group discussions and recording case studies. In addition, they received guidance on dealing with difficult emotional situations and referring people for counselling or accessing services and information on a need basis. The researchers from IRiZ supervised the training of the Research Assistants, and they moved in between the two trainings to ensure quality training was delivered.

Eleven data capturers were recruited, who were responsible for data entry. These data capturers participated in a 1 day in-house training for them to have a clearer understanding of the research, and their roles as defined for them. The *training workshops* covered a broad range of issues including (but not limited to):

- Ensuring a common understanding of the study's goals and objectives
- Ensuring a clear understanding of the items in the data collection tools and the processes and procedures to be followed during fieldwork
- Ensuring that all fieldworkers knew exactly how to navigate their way around the data collection tools and use the same response procedures to each question and probes.
- Ethical considerations and how they were to be handled

In order to enhance the effectiveness of the training sessions, each fieldworker received in advance and studied a detailed training manual on '*Critical Issues to Consider when Planning and Conducting Questionnaire Interviews*'. This generic document has been refined over the years to ensure that it is both detailed and clear enough to be used as a reference guide during training and in the field. It was adapted it for this specific study by including relevant examples, illustrations, etc.

On the last day of the training, the Research Assistants and Team Supervisors were asked to sign Confidentiality agreements (see Appendix ...) because of the sensitivity of the research. The data clerks also signed a Confidentiality agreement. (See Appendix ---)Also, field supervisors underwent additional training of quality control procedures to be followed during data collection.

2.5 Data Collection

Ten teams were constituted, which were deployed simultaneously in all the 10 provinces. There were 30 districts covered and each district was represented by a fieldworker. However, during fieldwork, the fieldworkers were organised into 10 teams, led by a Provincial Coordinator who assumed the role of Team Supervisor. The research team in each of these Provinces used predefined and identified registers of PLHIV from support groups in the ZNNP+ and Church groups' structures at district level. The respondents were randomly selected at two support groups (one in the ZNNP+ structures, and one from the church groups) at district level. The fieldworkers were responsible for administering the questionnaire, and conducting the FGDs. The teams were led by ZNNP+ provincial coordinators who were trained and assumed the role of Team Supervisors. The Team Supervisors ensured that all logistics for data collection at each selected site were in place while also ensuring that quality data were collected. Each supervisor was accompanied by a district representative, in which case if the supervisor was male, then the district representative was to be female and vice-versa.

IRI provided two senior supervisors who assumed an overall supervisory role throughout the period of data collection, which lasted three weeks in most cases. These senior supervisors offered technical backstopping and supervisory support to the 10 Team Supervisors. The 10 provinces in Zimbabwe were broken down into two regions i.e. Northern Region (Mashonaland

East, Central, West, Harare and Manicaland) and Southern Region (Matabeleland South and North, Bulawayo, Masvingo and Midlands).

2.5.1 Survey Administration

Trained fieldworkers were deployed to the various sites as per fieldwork schedule. They then interviewed respondents using the face to face interview method. After completing a survey questionnaire they handed them in to their team supervisor who then conducted quality control procedures. If the quality was not satisfactory then a questionnaire would be redone, if the quality was satisfactory the team supervisor would approve and store it in a pre-determined secure environment – as described during training. The questionnaires were collected by ZNNP+ who also ran quality control procedures on the data. Data was stored under lock and key until it was forwarded to the researchers for analysis.

Data Collection for Key Populations

Key Population 1: Sex Workers (SW)

The CeSHHAR (an organisation working with SWs) was approached and they facilitated interaction with 2 sex workers (SW) who are living positively with HIV (1 from the ³⁸Northern Region and 1 from the ³⁹Southern Region). Once they agreed to participate in the research they were trained and recruited as Research Assistants. The newly trained SW then identified, and interviewed more SWs from their network.

Key Population 2: Men having Sex with Men (MSM)

GALZ (an organisation working with gay, lesbian, bi-sexual and transsexual people) was approached and they facilitated contact with 2 MSM (1 from the Northern Region and 1 from the Southern Region) who are living positively with HIV. The 2 MSM were interviewed as participants and subsequently recruited and trained to interview other participants. They each identified 15 more MSM and interviewed them as part of the sample.

Key Population 3: Prison Inmates

The ZPCS assisted in the identification of 2 (one male and one female) prison inmates living positively with HIV who were interviewed and participants and then recruited and trained to interview other participants within their population. With the help of the Zimbabwe Prison and Correctional Services (ZPS) these two inmate each identified 15 of their peers, whom they interviewed. Thirty participants were interviewed as per target.

Key Population 4: PLHIV living with disabilities

The NCDPZ assisted the Researchers to identify 2 (1 from the Northern Region and 1 from the Southern Region) PLHIV with disabilities. The two (1 male and 1 female) were interviewed and trained, after which they each identified and interviewed their peers.

2.5.2 In-depth interviews with Key Informants

District level key informant interviews were conducted by the respective team-stored leaders. These interviews were conducted in a private setting where confidentiality could be ascertained. After recording, interviewers forwarded recordings to the researchers. The recordings were then downloaded and encrypted for security purposes. Transcription took place in a secure

³⁸ Northern Region-Harare, Mashonaland East, Mashonaland West, Mashonaland Central and Manicaland)

³⁹ Southern Region-Bulawayo, Matebeleland South, Matebelenad North, Masvingo and Midlands

environment. The data was then subjected to thematic content analysis and themes emerged from the data. Relevant quotes were then extracted for usage in the report.

The Purposive sampling method was used to identify this category of participants. They were identified in advance by the researchers, on the basis of their strategic importance in the national response to HIV. At the scheduled time, appointments were made with key informants. They were at this point informed of the objectives of the study and why their participation was key to the success of the study. The voluntary nature of participation was highlighted. On the interview date, consent was given and interviews were conducted in a private venue. A senior member of the research team (in this case the Senior Projects Manager) conducted the interviews. Sessions were recorded and transcribed by skilled transcribers. The information gathered from these interviews was of a technical nature and allowed researcher to understand the current national situation as it relates to HIV related stigma and other relevant HIV related issues. For this study, district level key informant interviews were conducted by the various team leaders. KIIs were conducted with the following;

Table 2: Key Informant Interview Participants

Province	District	Category of Informant
	Hwedza	District AIDS Coordinator
	Hurungwe	District AIDS Coordinator
	Murombedzi	District Social Services Officer
	Chinhoyi	Monitoring and Evaluation Officer
	Banket	Registered Nurse
	Zvimba	District AIDS Coordinator
		District Social Services Officer
		Monitoring and Evaluation Officer
		District AIDS Coordinator
		Monitoring and Evaluation Officer
	Registered Nurse	
Mashonaland Central	Mt Darwin	District Administrator
		District Nursing Officer
	Mazowe	District Nursing Officer
		District Administrator
Manicaland	Makoni	Ward Councillor
		Chief
	Mutasa	Religious Leader
		Religious Leader
Midlands		
Masvingo	Bikita	District AIDS Coordinator
		District Nursing Officer

		Assistant District Administrator
		Councillor
		Headmen
		Rep from the PA's Office
		District Administrator
Harare	Zengeza	District AIDS Coordinator
	Bulawayo	Programs Officer RAPT
		Provincial AIDS Action Committee Chairperson
		Director of HOCIC
		Local Councillor
		Manager PSI
		2 x District Chairperson ZNNP+
		Director of Zenzeleni Community Based Organization

At national level, In-depth interviews (see Appendix B for IDI Guide) were conducted with the following national stakeholders;

- National AIDS Council
- Ministry of Health and Child Care (AIDS and TB Unit)
- United Nations Population Fund (UNFPA)
- Joint United Nations programme on HIV/AIDS (UNAIDS)
- Gays and Lesbians Association of Zimbabwe (GALZ)
- International Network of Religious Leaders Living with or Affected by AIDS (INERELA)
- Anglican Relief and Development in Zimbabwe (ARDEZ)
- Zimbabwe National Network of People living with AIDS (ZNNP+)

2.5.3 Focus Group Discussions

The same procedure was followed for all focus group discussions, regardless of whether the participants were male or female, adolescents or adults. All focus group discussions were held in-doors (e.g. in classrooms, churches, rooms at clinics, etc). For each focus group, there was a moderator and a note-taker (observer). Females FGDs were facilitated by female moderators and note-takers while male FGDs were moderated by male researchers. This was done in order to ensure that participants were comfortable to discuss the issues openly with same-sex researchers.

Once the group was ready to start, the moderator started by thanking everyone present and proceeded to explain the purpose of the discussion as outlined in the training manual and as discussed extensively during training. Consent to proceed with the discussion was sought and granted by all present, after which the moderator asked for permission to record the discussion in order "not to miss anything that was said". Only after permission was given by all those present did the discussion start. Skilled facilitators guided the discussions appropriately and good quality data were collected from these discussions. At the end of the discussion, the participants were thanked and given an opportunity to ask any questions they had. The moderator and the observer

answered questions openly and truthfully. In cases where they did not have a clear answer to a question, the question was referred to the team leader who was always at hand to handle more complex questions from participants.

The FGDs consisted of between 8 and 12 participants. FGD participants were drawn from ordinary community members, community youth groups, and women's groups. Bi-lingual (Shona/English or Ndebele/English) moderators facilitated the focus groups. Discussions lasted approximately an hour and followed a semi-structured guide to ensure that specific issues to do with HIV related stigma were covered. Discussions also allowed for an open-ended exchange of information among participants. Participants were also asked to 'free list' the most common stigma and discrimination practices. After generating these lists, participants were asked to prioritize their responses. Such collated responses provided useful data about perceptions of people living with HIV, with a relative sense of their perceived importance. There were diverse groups, and homogeneous focus group discussions facilitated by trained and experienced moderators to ensure rich discussions and a focus on the subject of stigma and discrimination. The moderators for the FGDs were the fieldwork team supervisors who in this case were the 10 provincial coordinators. A district representative working directly with the supervisors in each of the districts was responsible for note taking.

Ethical Procedures during fieldwork.

All members of the research team signed Confidentiality agreements because of the sensitivity of the research (See Appendix G).

Participant consent procedures (see Appendix I for Informed Consent form) were implemented on site just prior to both the face to face interviews and the focus group discussions by both prospective interview respondents and FGD participants. Signed consent forms were obtained for each respondent and participant. All participants were made aware that their responses would remain anonymous and confidential. Indeed, while names were used initially to select potential participants, names were not used in any written reports. Instead, participants were only ever identified in notes and written reports by their gender (sex: Male/ female) or other non-uniquely identifying characteristics.

For the FGDs, participants were informed ahead of time about the researchers' intention to record the discussions, and about procedures to safeguard the audio files as well as related documentation.

After informed consent were obtained from all participants, the groups commenced with the moderator explaining:

- *the purpose of the discussion,*
- *ground rules to be followed,*
- *maintaining confidentiality,*
- *the use of pseudonyms or initials on "name" tags ,*
- *the need to audio-record for accurate transcription,*
- *completion of consent forms, and*
- *the role of the observer*

Once respondents were ready to begin and all preliminary questions or issues raised by the respondents had been adequately addressed, the discussion guide questions were asked in turn, followed by appropriate (neutral) probes to facilitate in-depth discussion. At the end of the discussion, respondents were thanked for their time and participation.

All interviews were recorded for subsequent transcription and translation. A total of 20 high quality Olympus and Phillips audio-recorders were utilized for this purpose. These recorders enabled the field team to download audio files onto the field supervisor's laptop as soon as possible during fieldwork. The supervisor then performed the necessary quality control processes, encrypted the file and e-mailed it to the Data Manager at IRiZ while fieldwork continued. In cases where the email system failed to work, the 10 team supervisors were responsible for delivering the data to the Data Manager at IRiZ. This was critical for the qualitative component as we provided feedback to in-field staff, enabling them to clarify some aspects with respondents while they were still in the field.

2.6 Data Quality

CSPro enabled the user and data-capturing manager to easily monitor and control the data capturing process since multiple data capturers are used to capture questionnaire data

A critical feature of the CSPro is that it allowed for double capturing. It processed the data on a case basis and the data were stored in ASCII text files described by data dictionaries. It also has a powerful common procedure language (CPL) to implement data entry control and edit rules. Once the data dictionaries were written up and the codes were created, the interface created within CSPro made the data entry process easy and error-proof. Thus, effective quality control mechanisms were implemented throughout the data coding and data cleaning processes.

Data cleaning involved:

- Running frequencies on each variable and making sure there were no out-of-range values in the data
- Running internal consistency checks on the data

What about the double transcription process used for qualitative data. Say something here.

2.7 Data storage

Data were stored securely at all stages. Survey questionnaires were kept under lock and key prior to analysis. After they were captured, the actual copies were still kept under lock and key, the digital data were encrypted and stored securely at all times.

2.8 Processing and Analysis of quantitative data

The questionnaires were numbered using a numbering machine. This enabled us to easily track the processing of each and questionnaire. Data capturing screens were developed using CSPro (The Census and Survey Processing System) software. CSPro is a specialized data capturing software package that combines the features of Integrated Microcomputer Processing System (IMPS) and the Integrated System for Survey Analysis (ISSA) in a single windows environment. CSPro enables the data-capturer and data-capturing manager to easily monitor and control the data capturing process in situations where multiple data capturers are used.

Data capturers were recruited and trained on how to capture data using the CSPro software. Double data entry was used and any discrepancies checked against the original questionnaire to ensure accuracy. Once the data from all questionnaires were captured, the data files were

exported to SPSS for statistical analysis. Standard data cleaning techniques were implemented (e.g. confirming all missing values against original questionnaires, checking for data integrity, cross-checking outliers on individual variables, etc.) and the clean data files were submitted to the IRI statistician and senior researchers for analysis and interpretation. The data was then analyzed by generating frequency tables and cross-tabulations.

In cases where inferential statistics were deemed to be necessary, measures of association (e.g. correlations and chi-squares) and tests of significance of difference (e.g. t-tests, ANOVA F values, etc) were computed using SPSS ver. 17. These tests of statistical significance were used to determine the extent to which observed relationships and/or differences were beyond chance (if $p < 0.05$; a significant difference or relationship was inferred to exist using CI=95%). Cross-tabulations were also performed on the data using the demographic variables (e.g. gender, age group, district, marital status, etc) and the data presented in the form of tables and graphs. Quantitative data interpretation was triangulated with the qualitative data in situations where this was deemed to be both feasible and appropriate.

2.9 Processing and Analysis of qualitative data

The audio files from FGDs and IDIs were transcribed first and then translated into English by two independent persons after which a validation process was performed to ensure accuracy. This was followed by QC procedures performed on all transcripts to ensure that they were of high quality.

The transcripts were analyzed using a procedure known as content analysis to identify key themes that emerged from the data, guided by the research questions under investigation for this research effort. The use of content analysis permitted the research team to identify core themes and nodes from the data, allowing the research team to proceed from the particular to the general. Also, in some cases, specific quotations which were relevant for providing deeper insights into the patterns observed from quantitative data were extracted and are included in the findings section of this report. The tape recorded sessions of the focus group discussions, in-depth interviews with national and community level stakeholders were transcribed.

Field notes, based on observations during fieldwork were also used to gain a deeper understanding of the contextual issues emerging from the study throughout both during fieldwork and at the data analysis stage

2.10 Ethical Considerations

The Medical Research Council of Zimbabwe (MRCZ) approved this research. The clearance certificate issued by the MRCZ is included in Appendix J to IRiZ. All field and concerned office staff were required to sign confidentiality forms. Below are some of the ethical requirements that we adhered to during and after the fieldwork:

- Obtaining informed consent from all respondents of the survey and participants of the FGDs before participating in the study.
- Voluntary participation in the study and explaining that participants had the right to withdraw from the study without any negative consequences.
- Ensuring the confidentiality of personal level data through a number of mechanisms (assigning participants to control identification numbers, making sure that no interviewers conduct interviews in their home areas, no interviews with either a relative or someone they know etc.

- Ensuring anonymity of participants by not writing their names or any other personally identifying information on record forms or anywhere else where their details can be accessed by people who are not involved in the project, etc.
- Secured data handling at all stages, (data was kept under lock and key and data files will be password protected) A drop box system was set up for all researchers to share the documents, surpassing the emails which are increasingly being hacked.
- Particular care was taken during the presentation of the research findings in that the information presented is sufficiently aggregated to ensure that no one community or individual can be identified.

STUDY LIMITATIONS

There were a number of limitations to the study which were related to the design and sampling methods employed. The perceptions and experiences of PLHIV who were not utilising public services for HIV/AIDS or were not part of community support groups may have differed from the experiences and perceptions documented in this report.

In addition the data collection period coincided with major public holidays meaning in some areas, participants were not readily available for fieldworkers to interview them as they had travelled.

WHAT IS IN THIS REPORT

The findings section of this report is structured in such a way as to reflect the various sections of the questionnaire that was used during the study. The questionnaire and is divided into the following sections:

- Background characteristics and Household composition of respondents
- Reported experiences of HIV related stigma and discrimination in the following settings; Social and family setting; work, health and education settings; internalised stigma and fears; in terms of the rights, laws and policies that relate to PLHIV and on the effecting of change (at household and community level) platform.
- The experiences of PLHIV as regards testing, disclosure, treatment and having children.

Where appropriate, findings from the qualitative data from individual interviews and case studies are included at relevant points throughout the report.

CHAPTER 3: FINDINGS

3.1 Background Characteristics

A total of 1905 respondents participated in the research; 725 (38%) were male and 1180 (62%) were females. Forty-five percent (n=864) of the respondents were adults aged between 40 – 49 years, 33% (32.9%, n= 626) were adults aged between 30 – 39 years and about 6% (5.8%, n=111) were participants aged 50 years and above. Respondents in the 20 – 24 years of age and 25 – 29 years of age constituted 4% and 9% of the respondents respectively. Only 3% were youth aged between 15 – 19 years of age. There was little difference in age distribution based on gender.

Table 3: Respondents disaggregated by gender and age

	Male		Female		Total	
	Number	Percent	Number	Percent	Number	Percent
Youth aged 15-19 years	31	4.3%	33	2.8%	64	3.4%
Adult aged 20-24 years	36	5.0%	41	3.5%	77	4.0%
Adult aged 25-29 years	51	7.0%	112	9.5%	163	8.6%
Adult aged 30-39 years	205	28.3%	421	35.7%	626	32.9%
Adult aged 40-49 years	346	47.7%	518	43.9%	864	45.4%
Adult aged 50+	56	7.7%	55	4.7%	111	5.8%
Total	725	100.0%	1180	100.0%	1905	100.0%

3.1.1. Length of Time living with HIV

Slightly over 40% (41.5%, n=788) have been living with HIV for 5 – 9 years, 37% (n=701) had lived with HIV for a period between 1 – 4 years. Only 6% (n=122) had lived with HIV for less than a year and 15% (n=286) had lived with HIV for 10 or more years.

Table 4: Length of time living with HIV

	Male		Female		Total	
	Number	Percent	Number	Percent	Number	Percent
<1 year	60	8.3%	62	5.3%	122	6.4%
1-4 years	298	41.3%	403	34.3%	701	37.0%
5-9 years	265	36.7%	523	44.5%	788	41.5%
10-14 years	77	10.7%	135	11.5%	212	11.2%
15+	22	3.0%	52	4.4%	74	3.9%
Total	722	100.0%	1175	100.0%	1897	100.0%

3.1.2. Residency

The different provinces had diverse participation rates with respondents from Harare province constituting 13% (n=253) of the respondents, 12% (n=219) were from Bulawayo province, and 10% (n=192) were from Matabeleland North province. Each of the remaining 7 provinces had participation rates of between 8% and 10% respectively (see Table 3)

The participants of this study were identified and invited to take part in this study because they were members of HIV support groups and also because they were members of specific key populations such as commercial sex workers and prisoners.

Table 5: Distribution of Respondents by Province

Province	Male		Female		Total	
	Number	Percent	Number	Percent	Number	Percent
Bulawayo	55	7.6%	164	13.9%	219	11.5%
Harare	62	8.6%	191	16.2%	253	13.3%
Manicaland	66	9.1%	106	9.0%	172	9.0%
Mashonaland Central	75	10.3%	104	8.8%	179	9.4%
Mashonaland East	60	8.3%	122	10.3%	182	9.6%
Mashonaland West	74	10.2%	109	9.2%	183	9.6%
Masvingo	93	12.8%	89	7.5%	182	9.6%
Matabeleland North	73	10.1%	119	10.1%	192	10.1%
Matabeleland South	89	12.3%	92	7.8%	181	9.5%
Midlands	78	10.8%	84	7.1%	162	8.5%
Total	725	100.0%	1180	100.0%	1905	100.0%

3.1.3. Sexual Activity and Relationship Status

Ninety eight percent (97.7%, n=1862) of the respondents reported that they were sexually active, of these respondents 703 (38%) were male and 1159 (62%) were female.

Nearly half of the respondents (48.6%, n=905) were married or cohabitating with a partner whom they lived with, whilst 23% (22.5%, n= 419) of respondents were widows/widowers. Nine percent were single (8.7%, n= 162) and 7% (7.2%, n=134) were in a relationship but were not living together (see Table 4 below). There were more widows (30.6%, n= 355) compared to widowers (9.1%, n= 64).

Table 6: Sexual Activity and Relationship Status

	Male		Female		Total	
	Number	Percent	Number	Percent	Number	Percent
Married or cohabitating and husband/wife/partner is currently living in household	451	64.2%	454	39.2%	905	48.6%
Married or cohabitating but husband/wife/partner is temporary living/working away from the household	46	6.5%	72	6.2%	118	6.3%
In a relationship but not living together	45	6.4%	89	7.7%	134	7.2%
Single	56	8.0%	106	9.1%	162	8.7%
Divorce/separated	41	5.8%	83	7.2%	124	6.7%
Widow/widower	64	9.1%	355	30.6%	419	22.5%
Total	703	100.0%	1159	100.0%	1862	100.0%

3.1.4. Questionnaire Survey Respondents

Table 5 below shows that close to 89% of respondents revealed that they did not belong to any of the key population categories used in this study. Of the study participants, there were however, more females than males who were members of support groups. Of the 12% of participants who belonged to the key populations, 6% (5.5%, n=104) were people living with disabilities, and 2% (2.2%, n=42) were commercial sex workers. Men having sex with men constituted nearly 2% (1.9%, n=36) of the participants, and another 2% (1.6%, n=30) of the participants were prison inmates.

Table 7: Type of Respondents

	Male		Female		Total	
	Number	Percent	Number	Percent	Number	Percent
Support group members	631	87.2%	1062	89.9%	1693	88.9%
Men having sex with men	25	3.5%	11	0.9%	36	1.9%
Sex workers	0	0.0%	42	3.6%	42	2.2%
PLWD	53	7.3%	51	4.3%	104	5.5%
Prison inmates	15	2.1%	15	1.3%	30	1.6%
	724	100.0%	1181	100.0%	1905	100.0%

3.1.5. Education

Only 5% (n=94) of respondents had no formal education, whilst 35% (n=661) has primary school education. Slightly over half (55%, n=1036) of the respondents had a secondary school level education and only 5% (n=96) had education beyond secondary school.

Table 8: Education Level

What is the highest level of formal education you have completed?		
	Frequency	Percent
No formal education	94	5.0%
Primary school	661	35.0%
Secondary school	1036	54.9%
Technical college/university	96	5.1%
Total	1887	100.0%

3.1.6. Employment

Almost half of the respondents were unemployed and not working at all (47.5%, n=889), whilst almost 20% (19.6%, n=376) were working fulltime as self - employed individuals. Only 11% (10.9%, n=203) had full time employment status as an employee and only 6% (5.7%, n=107) are part time employee (See Table 7) below.

Table 9: Employment Status

Current Employment Status	Frequency	Percent
In full time employment (as an employee)	203	10.9
In part-time employment (as an employee)	107	5.7
Working full-time but not as an employee (self - employed)	367	19.6
Doing casual or part-time work (self - employed)	304	16.3
Unemployed and not working at all	889	47.5
Total	1870	100.0

3.2 Experiences of Stigma and Discrimination

This section comprises of five sub sections namely:

- Experiences of HIV related stigma and discrimination
- Access to work, health and education services
- Internalised stigma
- The protection of rights of people living with HIV through law, policy or practice
- Effecting change

3.2.1 Experiences of HIV related stigma

Respondents were asked about their experience of stigma and discrimination in the last 12 months preceding the study. Overall, 65.5% of the study respondents reported that they had experienced one or more of the forms of stigma and discrimination detailed below.

The highest percentage (51.4%) of the respondents reported that they had been gossiped about, while 31.2% reported that they had been verbally insulted, harassed and/or threatened, while other forms of HIV related stigma that were reported include: exclusion from social gatherings (21%), physically harassed and/or threatened (19%), Partner experienced discrimination (15%), experienced psychological pressure or manipulation (12.4%), Excluded from family activities (11.7%), exclusion from religious activities or places of worship (10.6%), physically assaulted (8.6%), sexual rejection (7.5%) and discriminated against by other people living with HIV (7.5%). The table below shows that there was a statistically significant higher percentage of females compared to males who reported that they had been excluded from social gatherings, excluded from religious activities or places of worship, being gossiped about, verbally insulted, harassed and/or threatened, physically harassed and/or threatened. On the contrary, a significantly higher percentage of males compared to females reported that they had experienced sexual rejection.

Table 10: Experiences of Stigma and Discrimination in the 12 months preceding the study

	Male	Female	Total (N)	Chi-square tests of statistical significance	
				Value Df=1	Sig
Excluded from social gatherings	18.3%	22.7%	1869	5.13	0.024**
Excluded from religious activities or places of worship	8.6%	11.8%	1818	4.56	0.033**
Excluded from family activities	11.4%	11.9%	1818	0.14	0.710
Being gossiped about	48.0%	53.4%	1836	5.13	0.024**
Verbally insulted, harassed and/or threatened	28.0%	33.3%	1844	5.72	0.017**
Physically harassed and/or threatened	15.1%	21.4%	1852	11.37	0.001**
Physically assaulted	7.8%	9.0%	1841	0.81	0.369
Psychological pressure or manipulation	11.3%	13.1%	1780	1.32	0.250
Experienced sexual rejection	10.2%	5.7%	1767	12.70	0.000**
Discriminated against by other people living with HIV	7.1%	7.8%	1833	0.30	0.585
Partner experienced discrimination	13.5%	15.9%	1761	1.95	0.163

The table below does not show a clear pattern in terms of respondents who experienced the different forms of stigma and discrimination across age groups.

Table 11: Experience of Stigma and Discrimination, From Other People Disaggregated by Age

	15-19 years	20-24 years	25-29 years	30-39 years	40-49 years	50+	Total (N)
Excluded from social gatherings	14.1%	18.7%	16.0%	20.7%	22.0%	27.3%	1869
Excluded from religious activities or places of worship	12.7%	12.2%	9.0%	11.3%	9.8%	12.3%	1818
Excluded from family activities	6.5%	10.8%	9.9%	12.6%	12.2%	9.3%	1818
Being gossiped about	51.6%	45.9%	54.2%	54.8%	48.6%	52.8%	1836
Verbally insulted, harassed and/or threatened	31.1%	24.0%	32.7%	33.4%	29.4%	36.1%	1844
Physically harassed and/or threatened	12.7%	18.2%	19.1%	21.7%	17.1%	22.2%	1852
Physically assaulted	4.9%	17.1%	15.0%	10.8%	5.9%	3.7%	1841
Psychological pressure or manipulation	4.2%	12.9%	12.1%	13.9%	12.5%	6.5%	1780
Experienced sexual rejection	.0%	8.7%	8.8%	7.2%	7.2%	12.4%	1767
Discriminated against by other people living with HIV	6.7%	2.7%	6.8%	8.8%	7.4%	6.3%	1833
Partner experienced discrimination	14.3%	13.5%	16.5%	15.5%	14.9%	11.8%	1761

It is worth noting that all prison inmates reported that they had experienced one or more forms of stigma and discrimination in the 12 months preceding the study. Just over ninety percent (90.5%) of the sex workers, 77.8% of men having sex with men, 65.4% of the people living with disabilities and 64.1% of the respondents who were members of support groups reported that they had experienced one or more forms of stigma and discrimination in the 12 months preceding the study.

Table 12: Experiences of Stigma and Discrimination by Key Populations

	Number	Percent	Total
Members of support groups	1085	64.1%	1693
Men having sex with men	28	77.8%	36
Sex workers	38	90.5%	42
People Living with Disabilities	68	65.4%	104
Prison inmates	30	100%	30

The difference among respondents who reported experiencing one or more of the forms of stigma and discrimination in the 12 months preceding the study across age groups was not statistically significant. However, as shown in the table below a higher percentage (71.2%) was recorded amongst adults who were over 50 years old, and the lowest (55.8%) was recorded in the 20-24 years age group.

Table 13: Experiences of Stigma and Discrimination Disaggregated by Age

	Number	Percent	Total
Youth aged 15-19 years	42	65.6%	64
Adult aged 20-24 years	43	55.8%	77
Adult aged 25-29 years	105	64.4%	163
Adult aged 30-39 years	419	66.9%	626
Adult aged 40-49 years	561	64.9%	864
Adult aged 50+	79	71.2%	111

Exclusion from Social Gatherings

While it is clear that both men and women are still being discriminated against at social gatherings due to their HIV status, Table 10 above shows that fewer males (18.3%) compared to females (22.7%) reported being excluded from social gatherings. The respondents reported that they felt excluded and unwanted from social gatherings such as parties and funerals and this was buttressed by views from FGD participants and one female described discrimination at a social gathering in the following manner:

"...Women are more stigmatised. We see this at funerals, they don't want women who are positive to cook or dish food at funerals, sometimes when one is positive even at a gathering no one wants to sit with them as before. The positive sit alone and the negative sit on their own ..."

Another male responded in a case study in-depth interview who experienced discrimination at social gatherings had this to say:

"...People don't want to eat in my plates, I have my own plates. No one wanted to sit next to me, they say that I smell. They move away from me so that I do not sit next to them..."

A prison inmate added that:

"...We are excluded from cooking and sharing utensils..."

Exclusion from Religious Activities or Places of Worship

The church continues to harbour a number of PLHIV who do not come out in the open for fear of victimisation and being shamed amongst peers. As such, low percentages of both females (11.8%) and males (8.6%) and experienced exclusion from religious activities or places of worship. Over the years the church has taken a moralistic view of the pandemic and one male FGD participant weighed in and said:

"...The ways in which pastors are preaching in churches and at funerals is not good because they assume that the person who died of HIV was promiscuous. For example, I once attended a funeral, the pastor was saying we preach to you that you must have one partner but you don't listen but now see what happens you become positive. Some pastors give us as examples in churches..."

This was echoed by a female participant who felt that HIV is equated to sin in churches:

"...In churches they preach that PLHIV are sinners..."

One sex worker also felt that some religious leaders were misleading them into believing that they can cure the disease:

"...In churches some Pastors pray for us and they say they will remove the disease but some go and they still test positive..."

Being gossiped About

With regards to forms of stigma and discrimination, it must be noted that the highest proportions of respondents reported that they had been gossiped about compared to the other forms. Also, fewer males (48%) experienced being gossiped as compared to females (53.4%). The following quotes typify the experiences of participants who experienced being gossiped about;

One Male FGD echoed the following:

"...In the workplace there is stigma and people gossip about us..."

A female participant added that:

"...There is a lot of gossip about us especially when we fall sick, if we look good and our skin looks good they say it's the pills and if we add weight, they say it's the pills and if we talk back at them, they say we haven't taken our pills..."

Verbally Insulted, Harassed and/or Threatened

As is the case with most forms of discrimination, more females (33.3%), compared to males (28%) reported that they had been verbally insulted, harassed and/or threatened as a result of the HIV status. Focus Group Discussion (FGD) participants buttressed this view, and cited the

perpetrators of this form of abuse to be fathers, grandfathers and headmasters among other perpetrators, and this is evidenced by the following quotes:

One young female case study participant resonated that:

"...My grandfather used to ill treat me and he would say I have sexually transmitted diseases..."

Another adult female FGD participant alluded that:

"...My father is just very abusive in terms of this because even when I am just slightly sick, he will say its AIDS she is about to die. My father will tell everyone that I have AIDS and I am about to die and this really hurts me..."

A young male case study participant added that:

"...My headmaster always tells me that I am weak and it is not the school's duty to take care of such people so generally there are no changes in schools on eradicating stigma..."

Experienced Sexual Rejection

Sexual rejection was experienced by both gender as evidenced by table 10. There is a notable difference where more males (10.2%) experienced sexual rejection compared to females (5.7%).

A typical quote is from a male participant who alleged that:

"...I faced the problem of sexual rejection and my wife just left home when I tested positive..."

Another male FGD participant reiterated that:

"..Sexual rejection is being experienced. Women tend to say if you do not have protection you will not get anything and yet you are married..."

One female FGD participant echoed that:

"...A partner can refuse to have sex with you and say that your virus is too much (you have a lot of virus)

Another male FGD participant added that:

"...When we found out that I was positive and my wife was negative, problems began, she never wanted to sleep with me again, up to now she does not want to sleep with me..."

Perceived reasons for experienced stigma and discrimination during the last twelve months

The respondents to the study were asked to indicate the reasons why they experience HIV related stigma and discrimination. The table below shows that of the respondents who reported being excluded from religious activities, 63.4% of them said it was because of their HIV status. Also, more than half of the respondents who reported being excluded from social gatherings (59.2%) and being gossiped about (50.9%), revealed that it was because of their HIV status. With regards to those who had been assaulted physically, more than of them (57%) reported that this happened to them due to other unspecified reasons.

Table 14: Reasons for Experiencing Stigma and Discrimination in the 12 months preceding the Study

	Because of HIV Status	For other reasons	Because of HIV status and other reasons	Not sure why	Total (N)
Reasons for being excluded from social gatherings or activities	59.2%	9.9%	27.6%	3.4%	355
Reasons for being excluded from religious activities	63.4%	12.0%	19.4%	5.1%	175
Reasons for being excluded from family activities	30.6%	12.1%	19.1%	38.2%	157
Reasons for being gossiped about	50.9%	12.9%	32.9%	3.4%	918
Reasons for being verbally insulted, harassed and or threatened	41.0%	29.9%	25.8%	3.4%	532
Reasons for being physically harassed	33.4%	26.3%	37.9%	2.4%	338
Reasons for being physically assaulted	12.7%	57.0%	25.4%	4.9%	142

3.2.2 Access to accommodation, work, health and education services

Accommodation

While 86.9% reported that they had never been forced to change their place of residence or were unable to rent accommodation, 13.1% had been forced to change their place of residence or denied accommodation. A significantly higher percentage of females (15.1%) than males (10.1%) respondents reported that they had been forced to change residency or denied accommodation. One female respondent reported that she had been denied access to both food and accommodation as a result of disclosing her HIV status at home:

"...Food was withdrawn from me and I was always beaten. I was accused of wrong doing which I had not done. I was chased away from home several times..."

Work

Over twenty percent (20.6%) of the respondents reported that they had lost their job or another source of income, while 12.1% were denied employment or work opportunity and 9.1% had their job description or nature of work changed or refused promotion as a result of their HIV status. In all the three cases related to employment as shown in the table below the difference across gender was not statistically significant.

Table 15: Experience of Stigma and Discrimination in the Workplace

	Male	Female	Total	Chi-square tests of statistical significance	
				Value	Sig
Being forced to change place of residence or unable to rent accommodation	10.1%	15.1%	1828	9.52	0.002**
Lost a job or another source of income	18.8%	21.9%	1315	1.88	0.170
Refused employment or work opportunity	12.0%	12.1%	1408	1.37	0.504
Job description or nature of work changed or refused promotion	8.4%	9.6%	1165	0.58	0.448

It is worth noting that Harare has the highest number of respondents who reported being denied accommodation, loss of employment, denied work opportunities and changes in job description or nature of work or denied promotion. On the other hand, Masvingo had the lowest number of respondents who reported the same. In the remaining provinces there is no clear pattern across the response categories.

Being Forced to Change Place of Residence or Unable to Rent Accommodation

Some participants who had disclosed their status to their relatives were stigmatised to the point that they had to look for alternative accommodation as the situation had become unbearable. Table 15 shows that more females (15%) were forced to change place of residence compared to males (10.1%) as typified below;

One female participant reiterated that:

"...I disclosed my status to my relatives and they disowned me, they also told everyone, I had to move and live somewhere else..."

Another male participant with disability in case study had this to say:

"...I used to live at my father's home so I left because it had come unbearable. They said I should not have married because I can't see and I am sick but I wanted to have my own child who would take care of me. The people I live around with now I don't have a problem with them. The new community likes me..."

Lost a Job or another Source of Income

Table 15 shows that fewer males (18.8%) compared to females (21.9%) reported that they had either lost their job or another source of income because of their status. The following quotes from participants provides such as examples;

One female FGD participant resonated that:

"...When I got sick I was given indefinite leave from work, when I got back I found that they had already replaced me..."

Another female participate echoed that:

"...At work, HIV is not talked about. If people find out, you resign..."

A Male participant had this to say:

"...If your employer finds out that you are positive, you get fired..."

Job Description or Nature of Work Changed or Refused Promotion

For some participants, who had disclosed their HIV positive status to their employer, their job description or nature of work changed and some of them were refused promotion. This is typified by the following examples.

An FGD female participant said that:

"...In workplaces there are certain posts we can't hold because of our statuses and at times we do not even get the jobs..."

A male FGD participant added that:

“...At work place discrimination arises in promotions based one’s status...”

The table below shows that it is mainly respondents from Harare Province who reported that they had been exposed stigma and discrimination in securing work, with over half of the respondents from Harare reporting that they had lost a job or source of income. The other Provinces do not show much variations in terms of respondents who were exposed to stigma and discrimination in securing work due to their HIV status.

Table 16: Experiences of Stigma and Discrimination in securing work and Accommodation

	Being forced to change place of residence or unable to rent accommodation	Lost a job or another source of income	Refused employment or work opportunity	Job description or nature of work changed or refused promotion
Bulawayo	14.00%	16.7%	10.4%	8.1%
Harare	35.70%	53.8%	20.9%	24.1%
Manicaland	13.70%	31.6%	3.0%	13.2%
Mashonaland Central	19.90%	28.8%	13.2%	21.4%
Mashonaland East	11.00%	6.3%	1.0%	12.0%
Mashonaland West	19.00%	40.2%	9.0%	11.1%
Masvingo	2.00%	1.6%	.8%	4.0%
Matabeleland North	1.60%	17.3%	19.0%	9.8%
Matabeleland South	1.10%	2.2%	3.9%	12.8%
Midlands	2.50%	11.4%	4.5%	5.8%
Total (N)	1828	1315	1165	1408

Just below half (49.8%) of the respondents reported that they had been forced to change residency or rejected accommodation because of their HIV status in whole or in part, while a similar proportion of the respondents perceived that it was for other reasons. Only 0.4% of the respondents indicated that they were not sure why they had been forced to change residency or denied accommodation. With regards to loss of employment or another source of income, over half (51.1%) of the respondents reported that it was because of their HIV status in whole or in part, while 43% said that it was for other unspecified reasons, and 5.8% where not sure why this happened to them.

Table 17: Reasons for Experiencing Stigma and Discrimination in Securing Accommodation and Work Opportunities

	Because of HIV Status	For other reasons	Because of HIV status and other reasons	Not sure why	Total (N)
Being forced to change place of residence or unable to rent accommodation	20.3%	49.8%	29.5%	0.4%	227
Lost a job or another source of income	30.2%	43.0%	20.9%	5.8%	258.0

Reasons of HIV related loss of income and discrimination in the workplace

Of those who lost their income because of their HIV status, 45.3% reported that it was because of a combination of discrimination and poor health, while 23.9% said it was because of

discrimination by employer or co-workers, 21.4% felt obliged to stop work and 9.4% indicated that it was because of other unspecified reasons. With regards to change of job description or nature of work, of the respondents who reported the same, the data reveals that 46% felt obliged to stop work, while 33% were discriminated against by their employer or co-workers, 11% said it was a combination of discrimination and poor health and 10% cited other unspecified reasons.

Education

Respondents were asked if they or their children had experienced exclusion from attending school. Only 4.1% of the respondents reported that they had been dismissed, suspended or prevented from attending an educational institution as a result of their HIV status. When disaggregated by gender, the table below reveals that there was no difference between male and female respondents who were dismissed, suspended or prevented from attending an educational institution.

On the other hand, 80.6% of the respondents reported that their children had been dismissed, suspended, or prevented from attending an educational institution. A higher percentage of female compared to male respondents reported that their children had been dismissed, suspended, or prevented from attending an educational institution.

Table 18: Access to Education Services across Gender

	Male	Female	Total	Chi-square tests of statistical significance	
				Value	Sig
Dismissed, suspended, or prevented from attending an educational institution	4.2%	4.0%	1776	0.736	0.692
Child dismissed, suspended, or prevented from attending an educational institution	78.2%	82.1%	1569	5.985	0.050

When disaggregated by age, it is clear that higher percentages of adults who are 50 years and above compared to the other age groups, reported that either they or their children had been dismissed, suspended, or prevented from attending an educational institution.

Table 19: Access to Education across age

	15-19 years	20-24 years	25-29 years	30-39 years	40-49 years	50+	Total (N)
Dismissed, suspended, or prevented from attending an educational institution	14.8%	14.1%	13.1%	19.1%	15.2%	38.8%	1776
Child dismissed, suspended, or prevented from attending an educational institution	83.8%	72.4%	72.4%	81.2%	81.1%	88.6%	1569

Health Services

In the 12 months preceding the study, 6.3% of the respondents reported that they had been denied health services, including dental services because of their HIV status. The difference

between male and female respondents who were denied the health services was not statistically significant. Also, just over five percent (5.3%) of the respondents reported that they had been denied family planning services because of their HIV status. With regards to sexual and reproductive health services, 5.5% of the respondents were denied the services. For both family planning and sexual and reproductive health services the differences across gender were not statistically significant.

Table 20: Access to Health Services across Gender

	Male	Female	Total	Chi-square tests of statistical significance	
				Value	Sig
Denied health services, including dental services	6.1%	6.3%	1656	0.03	0.856
Denied family planning services	6.4%	4.6%	1633	5.77	0.056
Denied sexual and reproductive health services	6.2%	5.0%	1609	1.02	0.312

Access to health services was seen to be high across age groups, and consequently the table below shows low percentages of respondents who reported that they had been denied access to health services. It is noteworthy that none of the young people aged 20-24 years reported that they had been denied access to sexual and reproductive health services.

Denied Health Services

Table 20 shows the percentages of participants who were denied health services including dental services. While participants reported that they were denied health services, most of them said that it was indirect as mostly felt discouraged from accessing health services as a result of being ill-treated by health providers. Such experiences are described in the following quotes from male and female interviewees below:

A female FGD participant whose brother died after being refused treatment had this to say:

"...Treatment in hospitals is different e.g. I had a brother who was HIV positive he was given a starter pack so when nurses changed their duties at kuGomo (Harare Hospital) they would say uyu ndewe starter pack (this one is almost dying) and they pass on to other patients. He was unable to breathe and he died..."

A male responded echoed that:

"...In clinics there is serious discrimination as we are the last to be served, they serve everyone else first despite the fact that we were the first ones to get there..."

Table 21: Access to Health Services across different ages

	15-19 years	20-24 years	25-29 years	30-39 years	40-49 years	50+	Total (N)
Denied health services, including dental services	1.9%	9.0%	5.1%	6.2%	7.1%	1.9%	1656
Denied family planning services	4.3%	1.6%	10.3%	4.9%	5.2%	3.9%	1633
Denied sexual and reproductive health services	6.7%	.0%	8.2%	5.5%	5.8%	1.9%	1609

3.2.3 Internalised Stigma and Fears

In this sub section, the focus is on internalised forms of stigma which include feelings and fears and their effect on decision making and avoidance in the 12 months before the study.

Feelings

A similar percentage (18.9%) of respondents reported that they feel guilty and have low self-esteem respectively because of their HIV status. Also, 17.9% said that they blame themselves, while 16.7% feel ashamed, 16.5% said they blame others, 5.4% feel suicidal and 3.5% feel they should be punished because of their HIV status. The table below shows that a significantly higher percentage of male than female respondents reported that they feel guilty because of their HIV status. On the other hand, a significantly higher percentage of female than male respondents reported that they blame others for their HIV status.

Table 22: Self Stigma Experience across Gender

	Male	Female	Total	Chi-square tests of statistical significance	
				Value	Sig
I feel ashamed	17.1%	16.5%	1810	0.13	0.176
I feel guilty	21.6%	17.2%	1800	5.59	0.018**
I blame myself	18.8%	17.3%	1789	0.70	0.404
I blame others	11.0%	19.9%	1778	24.36	0.000**
I have low self esteem	18.2%	19.3%	1782	0.29	0.588
I feel I should be punished	3.1%	3.8%	1773	0.56	0.455
I feel suicidal	6.0%	5.0%	1791	0.77	0.380

Higher proportions of the young people aged between 15-19 years compared to other age groups reported that they feel ashamed (33.3%) and that they blame others (30.4%) for their HIV status.

Table 23: Self Stigma Experiences across the different age groups

	15-19 years	20-24 years	25-29 years	30-39 years	40-49 years	50+	Total (N)
I feel ashamed	33.3%	23.6%	22.2%	16.9%	13.2%	21.8%	1810
I feel guilty	15.0%	19.2%	21.7%	20.2%	17.8%	17.8%	1800
I blame myself	10.7%	19.7%	20.4%	19.8%	17.7%	7.8%	1789
I blame others	30.4%	21.4%	20.5%	15.3%	15.3%	15.8%	1778
I have low self esteem	17.0%	20.8%	26.5%	18.8%	18.2%	13.1%	1782
I feel I should be punished	10.7%	2.8%	2.7%	3.8%	3.3%	1.0%	1773
I feel suicidal	13.8%	8.5%	8.6%	6.9%	3.4%	1.0%	1791

I feel Suicidal

Table 22 shows that both males (6%) and females (5%) had suicidal intentions as a result of their HIV status. The following quote typify the experiences of study participant who had suicidal thoughts;

An example of a male respondent who felt suicidal comes from a case study interview:

“...I feel that dying is the only way out. When one is infected they should not infect other people too. They should get tested before they get sick so that when they take pills it will not be worse...”

A female participant in a case study who was pained by the way she was being treated and this mostly leads to participants having suicidal intentions had the following to say:

“...Instead of him protecting me so that others cannot mock me he is so quick to say to me, you should just die with your AIDS and this really hurts. Sometimes I answer that am I the first one with the AIDS because what he says really pains me, yet even better people some driving cars have AIDS...”

Fears

Respondents were asked to reveal whether they had fears to be either gossiped about, being verbally insulted, being physically harassed or threatened, being physically assaulted and afraid that they would be rejected sexually. It is clear that a higher percentage (37.2%) of the respondents reported that they fear being gossiped about. When asked of their other fears, 17% reported that they were afraid of sexual rejection, while 15.4% said that they feared being verbally insulted, with 9.2% fearing physical harassment, and 8.9% feared to be physically assaulted in the 12 months preceding the study. The table below shows that a higher percentage of females than males were afraid of being gossiped about while a higher percentage of the males than females reported fear of being verbally insulted, physically harassed, physically assaulted and sexual rejection because of their HIV status. However, in all these cases the difference between the male and female respondents was not statistically significant.

Table 24: Self Stigma Experiences across gender

	Male	Female	Total	Chi-square tests of statistical significance	
				Value	Sig
Being gossiped about	35.7%	38.1%	1456	2.17	0.538
Being verbally insulted	16.0%	14.9%	1231	0.25	0.619
Being physically harassed/threatened	11.0%	8.0%	1195	3.28	0.194
Being physically assaulted	10.5%	7.9%	1198	2.98	0.225
Afraid that someone would reject you sexually	18.5%	16.0%	1482	1.66	0.198

The 25-29, 30-39 and 20-24 age groups reported the highest percentages of respondents who were afraid of being gossiped about respectively.

Table 25: Self Stigma across the different age groups

	15-19 years	20-24 years	25-29 years	30-39 years	40-49 years	50+	Total (N)
Being gossiped about	35.6%	36.8%	46.3%	40.0%	31.9%	61.7%	1456
Being verbally insulted	9.3%	23.2%	18.1%	15.6%	14.2%	20.0%	1231
Being physically harassed/threatened	2.4%	19.6%	13.5%	10.2%	7.6%	4.0%	1195
Being physically assaulted	2.4%	20.4%	17.1%	8.4%	7.0%	14.8%	1198
Afraid that someone would reject you sexually	14.6%	19.0%	23.6%	19.8%	14.7%	9.5%	1482

Fear of Being Gossiped About

As shown in Table 22, both females (38.1) and males (35.7%) reported fear of being gossiped about due to their HIV status, and this was supported by FGD participants who were of the view that some people do not disclose their status because of fear of being gossiped about.

A typical quote from an FGD female participant is:

"...People do not want to disclose their status or even to get tested because they are afraid of getting laughed at, e.g when people found out that I was pregnant while my husband was positive they really laughed at me that how can you get pregnant for someone who is positive..."

A male participant echoed that:

"...People do not want to disclose because they cannot see the real support that those who have been open about their status are receiving, as a result they do not see the benefit of being open or finding out their status..."

Afraid that Someone Would Reject You Sexually

Disclosure of one's HIV status (if positive) is feared to be the basis for sexual rejection, and both male (18%) and female (16%) respondents reported that they were afraid that they would be rejected sexually. The following cases, as portrayed by some study participants strengthen the view that there is fear of sexual rejection:

One young male FGD participant reiterated that;

"...It is really hard to be comfortable to disclose my status because we are afraid of losing friends and partners... In general some people do not even want to disclose to their partners because of denial, fear of stigma and discrimination..."

Another female FGD participant restated that:

"...A lot of people are still not disclosing their statuses because they are scared of not getting spouses and some people cannot open up to their spouses..."

Decisions and Avoidance

Respondents also provided information on decisions they have made and things that they have decided due to their HIV status. Thirty seven percent (37.2%) of the respondents reported that because of their HIV status they decided not to have more children. Other decisions made by the respondents include not to get married (15.2%) and not to have sex (13.8%) among other things. Also, the respondents reported that they avoided going to the local clinic (2.8%) and going to the hospital (2.1%) when they needed to.

Significantly higher percentages of females compared to males reported that they decided not to get married, and they also decided not to have sex because of their HIV status.

Table 26: Avoidance of Social Interactions

	Male	Female	Total	Chi-square tests of statistical significance	
				Value	Sig
I have chosen not to attend social gatherings	5.2%	4.6%	1791	0.28	0.598
I have isolated myself from family and friends	4.0%	4.3%	1768	0.12	0.729
I took decision to stop working	2.6%	1.6%	1683	1.90	0.169
I decided not to apply for job or promotion	2.4%	2.3%	1656	0.002	0.963
I withdrew from education/training	2.6%	2.1%	1626	0.39	0.533
I decided not to get married	6.7%	20.4%	1681	58.22	0.000**
I decided not to have sex	7.9%	17.4%	1661	30.24	0.000**
I decided not to have more children	36.9%	37.4%	1697	0.04	0.840
I avoided going to local clinic/hospital	2.7%	2.8%	1725	0.02	0.886

A higher percentage of the adolescents aged 15-19 years compared to all the other age groups reported that they had chosen not to attend social gatherings. The percentages of respondents who decided not to get married or have sex gradually increases with age, while the other decisions and avoidances do not vary significantly across age groups.

Table 27: Avoidance of Social Interaction across different age groups

	15-19 years	20-24 years	25-29 years	30-39 years	40-49 years	50+	Total (N)
I have chosen not to attend social gatherings	13.6%	5.6%	8.0%	4.0%	4.3%	3.8%	1791
I have isolated myself from family and friends	.0%	6.8%	4.8%	5.6%	3.2%	3.9%	1768
I took decision to stop working	2.0%	2.9%	2.2%	2.6%	1.8%	.0%	1683
I decided not to apply for job or promotion	1.9%	.0%	2.3%	3.0%	2.4%	.0%	1656
I withdrew from education/training	6.7%	3.1%	1.6%	2.8%	1.7%	2.3%	1626
I decided not to get married	15.7%	14.5%	15.2%	13.0%	16.5%	17.0%	1681
I decided not to have sex	10.2%	9.0%	9.9%	12.7%	14.9%	21.7%	1661
I decided not to have more children	8.9%	26.1%	24.1%	35.6%	42.3%	43.9%	1697

I Have Isolated myself from Family and Friends

It was reported that some participants had to isolate themselves from their family and friends after they had disclosed their status. This was triggered by ill treatment they were receiving from their families or close friends. Table 26 shows that 4% males reported to have isolated themselves from their families and close friends while 4.3% females isolated themselves from their families and friends. The quotes from FGDs with a male and female participant illustrate:

"...I disclosed my status to my relatives and they disowned me, they also told everyone, I had to move and live somewhere else..."

"...I used to live at my father's home so I left because it had come unbearable. They said I should not have married because I can't see and I am sick but I wanted to have my own child who would take care of me. The people I live around with now I don't have a problem with them. The new community likes me..."

I decided not to have more Children

Some participants who felt that they still wanted to have children were refused by their spouses. This is typified by the following quotation:

"...My wife wanted to get the Depo injection as a way of protection but we went to the nurses and they explained that Depovera is a contraceptive so I asked her why she needed Depo and from that time she just left home..."

It is clear from the above findings that a number of PLHIV have internalised stigma and fears. They either have fears of being gossiped about, insulted, physically harassed/assaulted and being rejected sexually while subsequently they have made decisions not to attend social gatherings, to stop working, going to school, getting married, having sex and children as a result of their HIV status. In another case, one PLHIV before being exposed to a program to try and deal with self-stigma (Inquiry Based Self Reduction Programme), narrated the following:

"Before I started using the Work to deal with stress and self-stigma, I was always fighting in my mind. I was fighting against reality. I had never got a chance to confront my husband about infecting me with HIV. I had not forgiven him. I was that kind of a person who always asked why me. I blamed myself, God and thought the world is unfair. But I never got fulfilling answers from this introspection. I worried about my body shape which had changed because of taking ARVs [antiretroviral drugs]. I didn't take issues lightly. My health deteriorated to a point where I weighed somewhere between 53 – 55 kg which is not my ideal weight".

3.2.4 Rights, Laws and Policies

This section mainly focuses on the awareness of the Declaration of the Commitment on HIV/AIDS and National AIDS Policy as well as violations of rights experienced in various settings.

Awareness of key documents

Almost thirty percent (29.5%) of the respondents reported that they had heard of the 2001 Declaration of the Commitment on HIV/AIDS which protects the rights of people living with HIV. A significantly higher percentage of females than males reported that they had heard of the Declaration. With regards to hearing of the National AIDS policy, 57.2% of the respondents reported that they had heard about it. The difference between male and female respondents who heard about the National AIDS Policy was not statistically significant.

Table 28: Knowledge of Key HIV/AIDS related Policies

	Male	Female	Total	Chi-square tests of statistical significance	
				Value	Sig
Have you heard of <i>Declaration of Commitment on HIV/AIDS</i>	32.4%	37.8%	1872	4.61	0.032**
Have you heard of The National AIDS Policy	54.7%	58.7%	1615	2.51	0.113

Over two thirds (67.5%) of the respondents who had heard of the Declaration of Commitment on HIV/AIDS reported that they had read or discussed the content of the Declaration. Again, a significantly higher percentage of females compared to males reported that they had read or discussed the contents of the declaration. With regards to the National AIDS policy, of those that heard of it, 38.8% of them reported that they had read or discussed its contents. The difference between the male and female respondents who read or discussed the contents of the National AIDS policy was not statistically significant.

Table 29: Awareness of HIV/AIDS related Policies

If Yes, have you read or discussed its contents?	Male	Female	Total	Chi-square tests of statistical significance	
				Value	Sig
Declaration of Commitment on HIV/AIDS.	63.3%	70.7%	533	3.26	0.071
The National AIDS Policy	43.3%	35.8%	531	3.66	0.056

Any violations of rights

Just over twenty percent (21.2%) of the respondents reported that their rights as a person living with HIV had been violated in past 12 months before the study. Of those whose rights had been violated, 37.6% of them reported that they tried to get legal redress. When disaggregated by gender, an almost similar percentage of male and female respondents reported that their rights as a person living with HIV had been violated. However, of those whose rights had been violated a higher percentage of females (40.1%) compared to a lower percentage of males (33.6%) reported that they had tried to seek legal redress. The difference across gender was however not statistically significant.

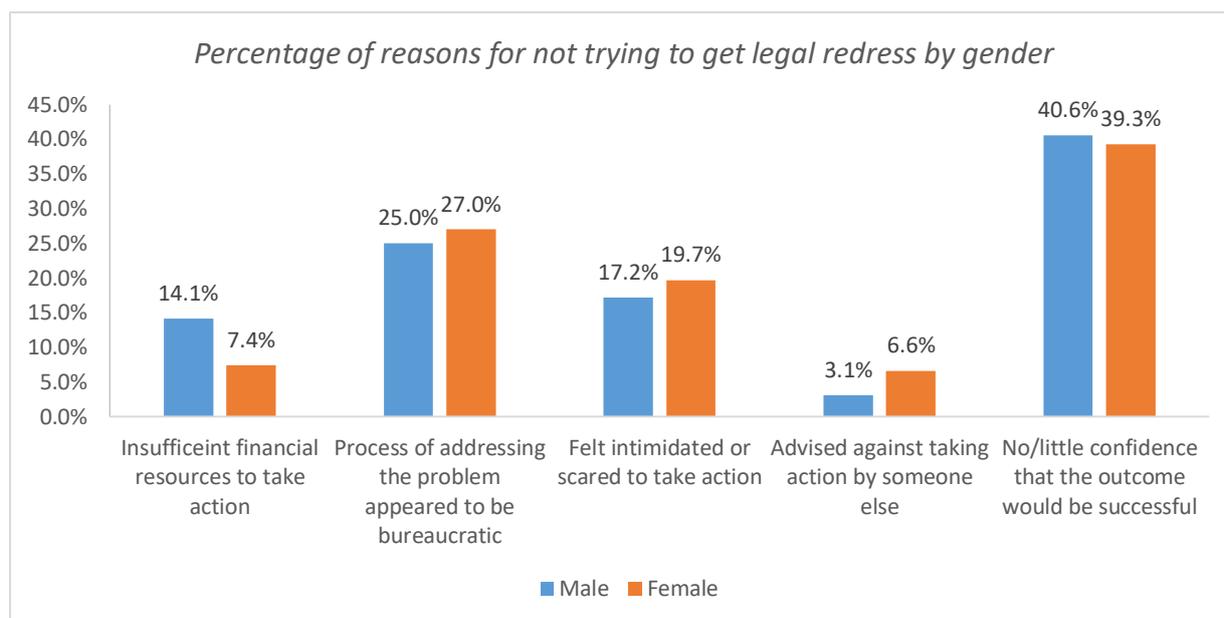
Table 30: Experience of Violation of Rights across Gender

	Male	Female	Total	Chi-square tests of statistical significance df=2	
				Value	Sig
Have any of your rights as a person living with HIV been violated in the last 12 months?	21.0%	21.4%	1832	3.63	0.163
If yes, have you tried to get legal redress for any abuse?	33.6%	40.1%	295	2.77	0.250

Seeking redress

Close to forty percent (39.8%) of the respondents who did not seek legal redress reported that this was so because no/little confidence that the outcome would be successful, while 26.3% reported that the process of addressing the problem appeared bureaucratic, 18.8% felt intimidated or scared to take action, 9.7% had insufficient financial resources to take action and 5.4% said that they had been advised against taking action by someone else. The difference in all the reasons for not seeking legal redress across gender was not statistically significant as shown in the graph below.

Figure 3: Reasons for Lack of Effort at attaining Legal Redress



3.2.5 Effecting Change

In this section the reactions of respondents to incidents of stigma and discrimination are explored. In this case, issues explored include awareness of potential sources of assistance when confronted with stigma and discrimination and participation in policy reform on HIV related stigma and discrimination.

Challenging Stigma and Discrimination

Over half (55.8%) of the respondents reported that they had confronted, challenged or educated someone who was stigmatising and discriminating against them in the 12 months preceding the study.

Knowledge of support organisations

Over two thirds (70.8%) of the respondents reported that they knew of support organisations that they can go to if they experience stigma and discrimination. Ninety two percent (91.8%) of the people living with disabilities compared to 75% of men having sex with men, 70.4% of support group members, 53.3% of prison inmates and 46.2% of sex workers reported that they knew of support organisations that they can go to if they experience stigma and discrimination. The difference on the knowledge of support groups across the types of respondents was statistically significant.

The table below shows the respondents' knowledge of the different types of organisations which provide support to those facing stigma and discrimination disaggregated by gender. The table shows that most commonly known support organisations across gender are people living with HIV support groups and networks of people living with HIV. Other types of organisations like local NGOs, faith based, legal practice, and human rights organisations were also cited though to a lesser extent. The difference across gender on the knowledge of support groups as shown in the table below was not statistically significant.

Table 31: Knowledge of Availability of HIV/AIDS Support Service Organisations

	Male	Female
People living with HIV support group	55.7%	51.4%
Network of people living with HIV	21.2%	23.3%
Local non-governmental organisation	1.6%	2.3%
Faith based organisation	0.5%	0.8%
A legal practise	7.9%	6.6%
A human rights organisation	1.4%	2.6%
National non-governmental organisation	0.3%	0.6%
National AIDS council or committee	8.7%	8.9%
International non-governmental organisation	0.3%	0.2%
UN organisation	0.5%	0.6%
Other	1.9%	2.7%
Total	368	619

Also, across different age groups, the commonly known support organisations were the people living with HIV support groups and the networks of people living with HIV.

Support provided by people living with HIV to others

Eighty nine percent (88.5%) of the respondents reported that they had provided support to other people living with HIV in the last twelve months before the study. Of the respondents who had provided support to other people living with HIV, the highest proportion (76.6%) of them reported that they had provided emotional support (e.g. counselling, sharing personal stories and experiences), while 13.7% had provided referral services and 9.8% provide physical support (e.g. providing money or food, doing errand for them) in the last twelve months preceding the baseline study.

The table below shows that there is no statistical significance between respondents who provided different forms of support to other people living with HIV across gender.

Table 32: Forms of Support Available for PLWHA across Gender

	Male	Female
Emotional Support	76.1%	76.8%
Physical support	11.7%	8.6%
Referral to other service providers	12.2%	14.6%
Total	540	893

Emotional and Physical Support

Study respondents reported that they support each other in various ways. This is typified by the following examples;

A female participant said that:

"...I went to get tested and I was told that I was positive. My dad told me that I should not worry as they were also living with HIV. I was stressing a lot and it was the year that I was writing my exams. I had to tell myself to be strong as I did not want to fail my exams..."

Another female case study participant professed that she had both emotional and physical support from her aunt after she was abused by her grandfather because she was HIV positive as evidenced by the below quote:

"...My grandmother then died in 2009, I then started to live with my grandfather, the father's brother wanted to take me but he refused with me. When people bring food for me, he would chase me from the house ad I go to my aunt's house. When the food is finished he would then come to fetch me. He started making stories for me such as I have sexually transmitted disease and I was having an affair with my brother and yet I am sick but it was all a lie. He would just want to chase me from the house. This caused me a lot of stress. He started chasing me with a stick to hit me so I run away and I took a stone wanting to through at him. He threw the stick at me and I hit him with a stone. My aunt took me and from then I have been staying with my aunt. People in the community like me and I don't have any other issues of discrimination..."

A young male case study participant recapped that:

"...I am close to my friends because some of them are also HIV positive. They disclosed their statuses later and told me that you are HIV positive; we are also HIV positive and were shy to tell you that..."

Ability to Influence Policies, Laws and Programmes

Just below thirty five percent (34.6%) of the respondents felt that they have power to influence decisions on legal/rights matters affecting people living with HIV, while 17.9% said they have power to influence local program/projects intending to benefit people living HIV. Other decisions that the respondents felt they have power to influence include, local Government policies (10.9%), national programmes/projects (6.1%), and international treaties/agreements (1%), while a quarter of the respondents reported that they did not have power to influence any of the given categories of decisions.

The table below shows a clear pattern that as respondents education level grew, they also felt that they have power to influence the varied decisions they were asked. The difference across education level was statistically significant in terms of the power to influence the varied decisions that the respondents were asked.

Table 33: Educational Attainment and perceptions of ability to influence decision making

	No formal education	Primary school	Secondary school	Technical college / university
legal/rights matters affecting people living with HIV	24.0%	30.8%	33.5%	45.0%
local government policies affecting people living with HIV	6.7%	11.1%	11.4%	16.3%
local projects intended to benefit people living with HIV	8.0%	15.2%	19.7%	23.8%
National government policies affecting people living with HIV	4.0%	3.2%	5.7%	6.3%
National programmes/projects intended to benefit people living with HIV	1.3%	5.8%	7.5%	3.8%
International agreements/treaties	1.3%	.9%	1.3%	.0%
None of these things	54.7%	33.0%	21.0%	5.0%
Total (n)	75	533	791	80

3.3 Experience of testing, disclosure, treatment and having children

3.3.1 Testing and Diagnosis

Just below a third (31.3%) of the respondents reported that they were tested for HIV because “they just wanted to know”. Also, 20.5% reported that they tested because of illness or death of their partner or family member, while 17.2% reported that they were referred due to suspected HIV related symptoms, 10.2% said it was because of pregnancy, 8.6% were referred by a clinic for STI treatment, 8.4% said their partner or family member had tested positive, and the remainder said it was either because of other reasons, preparing for marriage or sexual partners or because of employment. The reasons offered by male and female respondents for testing were significantly different as shown in table 34 below.

Disaggregation by gender revealed that the most commonly cited reason for undergoing HIV testing was “just to know my status”, thirty six percent of males and 28% of females cited this reason. However, in comparison, a higher percent of female (14.1%) than male (4.0%) respondents reported that they had undergone HIV testing because of pregnancy. Also, a higher percent of female (22.7%) than male (17.1%) respondents reported having undergone HIV testing due to an illness or death of their partner or family member. On the other hand, more male (10.3%) than female (7.5%) respondents undertook an HIV test because of a referral by a clinic following contracting sexually transmitted infections and more male (10.4%) than female (7.2%) respondents had undergone HIV testing because a Husband/Wife/Partner/Family member tested positive.

Table 34: Reasons Offered for Undergoing HIV Testing across Gender

	Male	Female
Employment	1.2%	.8%
Pregnancy	4.0%	14.1%
To prepare for marriage or sexual relationship	1.9%	.6%
Referred by a clinic for STI	10.3%	7.5%
Referred due to suspected HIV related symptoms	17.6%	16.9%
Husband/Wife/Partner/Family member tested positive	10.4%	7.2%
Illness or death of Husband/Wife/Partner/Family	17.1%	22.7%
I just wanted to know	36.2%	28.2%
Other	1.3%	2.0%
Total (n)	680	1086

Referred Due to Suspected HIV Related Symptoms

Some interviewees stated that testing was referred/ recommended/encouraged and they took the decision voluntarily. For example the following participants narrated the following experiences:

“...I realised i was positive in 2008 and i got two doses of treatment since my immune system was already beggared. I was encouraged by a colleague to go and get tested. I was already sick when I got tested...”

"...I started drinking pills in 2009. I was encouraged to get tested and I went to St Marys Hospital for the nurses to check me, and they found me positive..."

Illness or death of Husband/Wife/Partner/Family

Table 34 shows that most cited reason for getting tested was just to know their status or followed by death of a family member/wife/husband, therefore being referred for HIV testing. Both females (22.7%) and males (17.1%) reported that they got tested due to illness or death of spouse/partner.

One male case study participant echoed the following:

"...When my wife died, i was diagnosed in 2009. I got very sick, was admitted and I was tested. My legs are powerless. I used to have continuous running stomach, urinating was very painful, the running stomach was mucous only..."

A young female participant added that:

"...I started by losing appetite and I was tested. I couldn't eat so I could not take my medication. I used to lie to my grandmother that I had taken the pills and she then would put the pills in water to that I take them. This happened in 2007..."

Table 36 below details reasons given by respondents for undergoing an HIV test disaggregated by age. Slightly less than a fifth (18.3%) of those aged 25 – 29 years and almost 17% of those aged 30 – 39 years underwent HIV testing because of a pregnancy. Nearly a third (29.9%) of participants who were 50 years of age or more went for HIV testing due to HIV related symptoms. Almost one in three of participants aged 15 – 19 years reportedly underwent HIV testing due to illness or death of a family member whilst almost a quarter (24.1%) of those aged 40 – 49 years and 24.1% of those aged 50 years and above tested for HIV because of death of a spouse/partner/family member.

Table 35: Reasons Offered for Undergoing HIV Testing across Age

	15-19 years	20-24 years	25-29 years	30-39 years	40-49 years	50+
Employment	.0%	4.1%	2.0%	.7%	.9%	.0%
Pregnancy	1.7%	9.5%	18.3%	16.5%	5.6%	3.4%
To prepare for marriage or sexual relationship	.0%	2.7%	2.6%	1.0%	1.0%	.0%
Referred by a clinic for STI	5.1%	12.2%	5.2%	8.7%	9.1%	8.0%
Referred due to suspected HIV related symptoms	27.1%	10.8%	8.5%	16.0%	18.2%	29.9%
Husband/Wife/Partner/Family tested	11.9%	8.1%	11.1%	6.9%	8.9%	6.9%
Illness or death of Husband/Wife/Partner/Family member	30.5%	12.2%	17.0%	15.8%	24.1%	24.1%
I just wanted to know	18.6%	37.8%	34.6%	32.8%	30.2%	27.6%
Other	5.1%	2.7%	.7%	1.6%	2.0%	.0%
Total (n)	59	74	153	576	817	87

Table 37 below details the responses of participants when they were asked if the decision to test for HIV was voluntary, due to pressure from other people, due to coercion or if they were tested without their knowledge. Over half (51.1%) of the respondents reported that whilst they underwent HIV testing it was due to pressure from other individuals, 42% of respondents tested on a voluntary basis, 2.4% were coerced into testing, and only 1.8% were tested without their knowledge.

Table 36: Influencers behind Decisions to Get Tested across Gender

Decision ownership	Male	Female
I took the decision to be tested myself	41.0%	42.9%
I took the decision to be tested, but it was under pressure from others	51.1%	51.1%
I was made to take an HIV test (Coercion)	3.2%	1.8%
I was tested without my knowledge	4.7%	4.1%
Total (n)	661	1041

There were varied responses that were given by study participants across the different age groups as it related to getting tested for HIV. Of those aged between 15 – 19 years of age, almost two fifths (37.7%) reported that their decision to test for HIV was entirely voluntary, almost a third (34.4%) said they undertook testing but under pressure from others, whilst almost one in three participants (27.9%) were tested without their knowledge.

About half of the respondents aged 20 - 24 years of age disclosed that they tested under pressure from others, 52.4% of participants aged 25 - 29 years were tested on a voluntary basis, and almost two thirds (59.5%) of participants aged 50years and above were tested under pressure from others.

Table 37: Influencers behind Decisions to Get Tested across Age

	15-19 years	20-24 years	25-29 years	30-39 years	40-49 years	50+
Yes, I took the decision myself to be tested(i.e. it was voluntary)	37.7%	30.6%	52.4%	45.6%	40.5%	31.0%
I took the decision to be tested, but it was under pressure from others	34.4%	50.0%	43.4%	48.5%	54.8%	59.5%
I was made to take an HIV test (coercion)	.0%	4.2%	2.1%	1.6%	2.7%	4.8%
I was tested without my knowledge- i only found out after the test had been done.	27.9%	15.3%	2.1%	4.2%	2.0%	4.8%
Total	61	72	145	550	790	84

Counselling during HIV testing

Respondents were asked if they had received any counselling as they were testing for HIV. Over ninety percent (91%) of the respondents reported that they had received both pre - test and post - test counselling when they were undergoing HIV testing. Only 3.6% of respondents received only pre - test counselling and 3.5% of respondents received only post - test counselling. Only 1.7% reported that they had not received any counselling as they underwent HIV testing.

When disaggregating by gender, 91% of male and again 91% of female respondents received both pre and post HIV test counselling. Only 5% of males and 3% of females received only pre - test HIV counselling respectively, whilst 4% of male and another 4% of female respondents received only post – test HIV counselling services. This is detailed in table 39 below.

Table 38: Access to Pre Test and Post Test HIV Counselling

	Male	Female
I received both pre- and post-HIV test counselling	91.4%	91.0%
I only received pre-test HIV counselling	2.8%	4.2%
I only received post-test HIV counselling	3.8%	3.4%
I did not receive any counselling when I had an HIV test	2.0%	1.5%
Total (n)	688	1098

3.3.2 Disclosure and Confidentiality

Less than five percent (4.3%) of the respondents reported that a health care professional (for example, a doctor, nurse, counsellor) had told other people about your HIV status without their consent.

Respondents were asked about the first time that they disclosed their status to the different categories of people in their lives. The data suggests that people living with HIV and AIDS disclosed their status themselves without interface from a third party.

Within the **family context**, 81 % disclosed to their children themselves with only 8% reporting that their children were not aware of their HIV status. Seventy eight percent disclosed their status to a spouse or partner with only 3% saying their spouse/partner did not know of their HIV Status. Seventy percent disclosed to adult family member whilst a low 13% said someone other than themselves told adult family members with their consent.

Within the **community context**, 68% of respondents disclosed to friends and neighbours, with only 12% reporting that their friends and neighbours did not know of their status. Eighty five percent disclosed their status to other people living with HIV. It is interesting to note that **only** 31% of respondents disclosed their status to community leaders, furthermore, 33% said their community leaders were not aware of their status.

In the **workplace context**, 22% of respondents had disclosed their status to their employers, with 20% saying that their employer was not even aware of their status. Only 14% of respondents had disclosed their status to their clients with 31% saying their clients were not aware of their status. Only 35% of respondents had told co-workers of their status. Almost 40% of respondents had not told their co-workers of their status.

Within the **religious context** only 31% of respondents told their leaders of their status with more respondents (33%) confirming that their religious leaders did not know of their status.

Within the **health services context**, over half of the respondents confirmed having disclosed their status to health care workers (53%), and social workers/counsellors (60%).

Within the **education context**, only 20% of respondents had told teachers of their status, and 32% confirmed that their teachers were not aware of their HIV status.

Table 39: Experiences at Disclosure of HIV positive Status

	I told them	Someone else told them with my consent	Someone else told them without my consent	They don't know my HIV status	Not Applicable	Total (N)
Husband/ Wife/ Partner	77.9%	2.0%	0.4%	3.4%	16.4%	1651
Other adult family members	70.2%	13.4%	1.9%	7.8%	6.7%	1698
Children in your family	81.6%	3.5%	1.4%	7.7%	5.8%	1719
Your friends/ neighbours	68.3%	8.2%	4.3%	11.9%	7.4%	1712
Other people living with HIV	85.4%	6.7%	2.0%	2.6%	3.4%	1714
Co-workers	35.0%	2.2%	1.8%	21.1%	39.9%	1482
Employer/ boss	22.3%	0.7%	1.4%	19.9%	55.7%	1435
Client	13.5%	1.2%	1.1%	30.9%	53.3%	1196
Injecting drug partners	6.8%	1.1%	1.2%	21.8%	69.2%	1106
Religious leaders	30.8%	2.9%	1.4%	32.9%	32.0%	1588
Community leaders	31.4%	4.8%	1.9%	33.8%	28.1%	1497
Health care workers	53.1%	4.6%	1.9%	21.8%	18.5%	1506
Social workers/ counsellors	59.6%	2.3%	1.5%	16.2%	20.4%	1493
Teachers	20.2%	1.9%	1.5%	31.6%	44.9%	1459
Government officials	10.6%	0.8%	1.5%	33.1%	54.0%	1452
Media	5.4%	1.0%	1.7%	32.1%	59.9%	1454

Respondents were asked of the reactions of different people in their lives at disclosure of their status. Thirty four percent found their spouses/intimate partners to be very supportive, 43% said children were very supportive. Thirty one percent of respondents experienced Social workers as very supportive, a further 27% of respondents said healthcare workers were very supportive. Approximately 11% of respondents felt their spouse/partner was very discriminatory at their disclosure. Table 41 below details these responses.

Table 40: Responses of Significant Others to Disclosure of HIV positive Status

	Very discriminatory	Discriminatory	No different	Supportive	Very supportive	Not Applicable	Total (N)
Husband/Wife/Partner	11.2%	3.7%	9.4%	19.2%	33.9%	22.6%	1170
Other adult family members	9.2%	5.8%	9.8%	34.7%	34.7%	5.7%	1630
Children in your family	8.2%	3.1%	9.6%	29.0%	42.5%	7.7%	1620
Your friends/ neighbours	7.6%	3.8%	12.0%	39.8%	28.7%	8.1%	1572
Other people living with HIV	5.8%	2.9%	10.0%	35.6%	32.6%	13.1%	1474
Co-workers	4.4%	3.9%	7.9%	19.2%	18.5%	46.0%	1310
Employer/boss	5.1%	2.9%	7.4%	11.5%	15.8%	57.3%	1307
Client	4.0%	2.0%	7.9%	11.3%	15.3%	59.5%	1310
Injecting drug partners	3.3%	2.1%	6.8%	8.5%	14.3%	65.0%	1288
Religious leaders	5.0%	2.5%	8.4%	16.1%	20.0%	48.1%	1363
Community leaders	5.8%	2.0%	10.6%	13.7%	19.6%	48.2%	1327
Health care workers	5.5%	2.8%	9.3%	24.1%	27.3%	31.0%	1234
Social workers/ Counsellors	3.4%	1.7%	8.5%	23.9%	31.3%	31.2%	1187
Teachers	3.7%	1.2%	10.1%	13.9%	19.2%	51.8%	1185
Government officials	3.8%	0.7%	8.5%	9.2%	15.8%	62.0%	1216
Media	3.3%	1.0%	9.8%	7.4%	14.5%	64.0%	1258

3.3.3 Treatment

Respondents were asked how they described their health – an overall 30% described their health status as “fair”, a further 27% termed their health as “good”, 20% said their health was “excellent”, 18% reported that their health was “very good” and approximately 4.5% said their health was “poor”.

A similar trend with both male and female respondents was observed. Both sexes reported that their health was mainly “good” or “fair”. Only 17% of male respondents and 19% of females described their status of their health as “very good”. Three percent of males and 5% of females described their health status as “poor”.

Table 41: Self-Reported Health Status across Gender

	Excellent	Very good	Good	Fair	Poor	Total (n)
Male	21.3%	16.5%	29.2%	29.8%	3.1%	732
Female	19.5%	19.0%	26.0%	30.2%	5.3%	1155

Almost 40% of participants in the 15 – 19 years age category described their health as excellent, with 27% describing their health as “good” and 23% as “very good”. Participants in the older age categories had less of a propensity to describe their health as ‘excellent’, with most describing their health as “good” or “fair”. Table 43 describes this situation in detail.

Table 42: Self-Reported Health Status across Age

	15-19 years	20-24 years	25-29 years	30-39 years	40-49 years	50+
Excellent	35.9%	16.9%	24.5%	20.6%	18.9%	14.4%
Very good	23.4%	20.8%	27.0%	17.9%	16.1%	16.2%
Good	26.6%	24.7%	25.2%	26.9%	28.9%	21.6%
Fair	14.1%	32.5%	17.0%	29.1%	32.3%	44.1%
Poor	.0%	5.2%	6.3%	5.5%	3.7%	3.6%
Total (n)	64	77	159	621	855	111

When description of health status was disaggregated by those who were members of support groups and those who were part of key populations, it was interesting to note that 33% of men having sex with men described their health as “fair” or “excellent”. While 44% of sex workers described their health as “fair”, 22% described their health as ‘poor’ less than 8% described their health as excellent or very good.

Seventy three percent of People living with disability said their health was “good” and 53% of inmates said their health was very good.

Table 43: Self-reported Health Status across Members of Support Groups and Members of Key Populations

	Excellent	Very good	Good	Fair	Poor	Total
Support groups	20.7%	18.9%	25.4%	31.0%	4.1%	1676
Men having sex with men	33.3%	13.9%	11.1%	33.3%	8.3%	36
Sex workers	7.3%	7.3%	19.5%	43.9%	22.0%	41
PLWD	13.5%	1.0%	73.1%	8.7%	3.8%	104
Prison inmates	16.7%	53.3%	.0%	30.0%	.0%	30

The data suggests that respondents have access to ART regardless of whether or not they are in support groups or are members of key populations. Prison inmates reported that they had access to ART all the time, sex workers had access to ART 7 times out of ten.

Table 44: Access to ART across Key Populations

	Yes	No	Total
Support groups	80.0%	20.0%	1388
Men having sex with men	82.9%	17.1%	35
Sex workers	70.7%	29.3%	41
PLWD	94.2%	5.8%	104
Prison inmates	100.0%	.0%	30

Associated with health status, is the treatment component. The gender differential was considered important in terms of access to treatment. More males (84%) than females (80%) had access to ART even if they were not taking the medication. The data shows that there is a relationship between gender and access to ART ($p < 0.05$). Concerning access to medication opportunistic infections even if medication is not being taken, again more males (79%) compared to females (72%) had access. The difference was statistically significant ($p < 0.05$) indicating that

gender plays a significant role in terms of access to medication for treatment of opportunistic infections.

When respondents were asked if they had had constructive discussion relating to HIV options available, 66% of males and 65% of females confirmed that they had had such discussions with healthcare workers. There was no relationship between gender and the experience of these discussions.

Table 45: Access to Treatment across Gender

	Male	Female	Total	Chi-square tests of statistical significance		
				Value	Sig	df
Do you have access* to antiretroviral treatment, even if you are not currently taking it?	83.9%	79.3%	1598	14.02	0.001	2
Are you currently taking any medication to prevent or to treat opportunistic infections?	16.7%	59.8%	1860	0.63	0.426	1
Do you have access* to medication for opportunistic infections, even if you are not currently taking it?	79.1%	72.0%	1819	14.74	0.002	3
Have you had a constructive discussion with a health care professional(s) on the subject of your HIV related options	66.2%	65.4%	1855	0.10	0.752	1
Have you had a constructive discussion with a health care professional(s) on other subjects such as your SRH, sexual relationship(s), emotional well-being, drug use etc.	65.4%	64.6%	1840	0.12	0.726	1

3.3.4 Having children

84.8% (n=1616) of the respondents reported that they had children. Of these, 83% reported that after diagnosis they received counselling on their reproductive options, whilst only 13% had not received counselling. Almost half (42.8%) of respondents were advised not to have children, whilst another 50% of respondents were not given this advice. Only 10% of respondents were ever coerced into sterilisation because of their HIV status. When asked if respondents' ability to obtain ART was conditional to usage of certain forms of contraception only 11% of respondents said this was the case.

Table 46: Experiences of Counselling Services on Suitable Reproductive Health Options

Counselling experience	Yes	No	Don't know	Not Applicable	Total (N)
Since being diagnosed have you ever received counselling about your reproductive options	82.8%	13.0%	4.8%	0	1805
Has a health professional advised you not to have children since you were diagnosed with HIV	42.8%	50.2%	7.0%	0	1774
Has a health professional ever coerced you into being sterilised since you were diagnosed with HIV	10.1%	81.9%	8.0%	0	1753
Is your ability to obtain ART conditional on the use of certain forms of contraception?	11.4%	79.5%	1.3%	7.9%	1723

Coercion in relation to pregnancy, delivery method and infant feeding options

Female respondents were asked to indicate if they had experienced coercion from a health care professional regarding pregnancy, delivery method, and infant feeding options in the previous 12 months:

- Close to five percent (4.8%) of the female respondents reported that they had been forced to terminate pregnancy.
- With regards to delivery methods, 6.8% of the females reported that they had been coerced by a health care professional e.g. forced to have a caesarean section.
- Under nine percent (8.9%) of the mothers reported that they had been forced to adopt infant feeding practices wanted by the health care professional who attended to them.

CHAPTER 4: DISCUSSION, RECOMMENDATIONS AND CONCLUSION

4.1 Discussion

4.1.1 Experiences of HIV related stigma

Close to two thirds of the respondents reported that they had experienced at least one of the forms of stigma and discrimination as a result of their HIV status. It is worth noting that the respondents mostly faced gossip at workplaces at home and even in the community. However, it is important to note that they also had been verbally insulted, harassed and/or threatened, and had been excluded from social gatherings, family and religious activities. As is the case in other countries, a significantly higher percentage of women compared men experienced stigma and discrimination in the form of being excluded from social gatherings, excluded from religious activities or places of worship, being gossiped about, verbally insulted, harassed and/or threatened, physically harassed and/or threatened. On the contrary, a significantly higher percentage of males compared to females reported that they had experienced sexual rejection.

With regards to the key populations, all the prison inmates who participated in the study reported that they had experienced at least one form of stigma and discrimination as a result of their HIV status. The sex workers, MSM and People with Disabilities also reported higher levels of stigma and this was purported to be because they face double stigma (*both because of their HIV status and their status in society which is not easily acceptable*).

While there are other reasons that could cause stigma and discrimination, the data suggests that it is mainly because of one's HIV status that they are stigmatised if their living with HIV.

4.1.2 Access to accommodation, work, health and education services

While the proportion of respondents who reported that they had been denied accommodation is low, again a significantly higher number of women compared to men reported that they had been forced to change residency or denied accommodation. Also, a fifth of the respondents reported that they had either lost their job or their income as a result of their HIV status. With regards to education, only a few (4%) of the respondents reported that they had been either dismissed, suspended or prevented from attending an educational institution as a result of their HIV status. Notably, however, there remains a challenge with most of the children of PLHIV reportedly being dismissed, suspended, or prevented from attending educational institutions.

4.1.3 Internalised Stigma and Fears

PLHIV are usually faced with a number of decisions to make, for example decisions to or against working, going to school, attending social gatherings, getting married, not to have more children and having sex among other things. However, sometimes because of their feelings and fears, they are normally caught in between, and not sure what to do. In this study, the PLHIV noted that they feel ashamed, guilty, now have a low self-esteem and they blame themselves. During fieldwork, the researchers would refer respondents who reported that they felt suicidal, however, it must be noted that while the percentage is low, self-stigma is a challenge that has led other people to even commit suicide. Together with these feelings, PLHIV registered that they have fear being gossiped about, physically and verbally abused and sexual rejection. It was reported that due to these feelings and fears, people find it hard to disclose their status to their families, church mates, peers and even to their partners.

4.1.4 Rights, Laws and Policies

This study only focused on the awareness of two documents (the Declaration of the Commitment on HIV/AIDS and National AIDS Policy). The data suggests that these documents are generally not known amongst most PLHIV, though a higher percentage reported that they had heard of the Declaration of the Commitment on HIV/AIDS compared to the National AIDS Policy. A fifth of the respondents reported that they felt that their rights as a PLHIV had been violated. This was mainly with regards to access to basic services such as health, education and employment, where they felt that they are being treated unfairly as a result of their HIV status. The respondents also reported that when they felt violated, they did not seek legal redress because they felt that the process of reporting was bureaucratic, and they had little confidence that the case would be dealt with favourably. Also, since the legal services are out of their financial reach, they would not attempt to seek legal redress, for example, companies have company lawyers, and as such they always have the advantage.

4.1.5 Effecting Change

It is important to assess awareness levels of PLHIV in terms of services that are available to them, and most importantly to assess whether they have the strength and know-how to impact the lives of their peers who may be still struggling to find their feet. Clearly, the data suggests that the respondents knew of support organisations that they can go to if they experience stigma and discrimination, however, it must be also noted that most respondents were drawn from PLHIV support groups. The data suggests that the commonly known support organisations are people living with HIV support groups and networks of people living with HIV. Other types of organisations like local NGOs, faith based, legal practice, and human rights organisations were also cited though to a lesser extent.

It is encouraging to note that high proportions of the PLHIV reported that they had provided emotional support (e.g. counselling, sharing personal stories and experiences) to other PLHIV. The PLHIV are key stakeholders, and should be consulted extensively in the development of any policies and programs that are related to the HIV pandemic. However, only a third of the respondents felt that they have power to influence policy decisions on legal/rights matters affecting people living with HIV.

4.1.6 Testing and Diagnosis

There are a number of reasons why people get tested, and in Zimbabwe, there are programs such as Voluntary Counselling and Testing (VCT) Awareness, Prevention of Mother To Child Transmission (PMTCT) among others which encourage all people to get tested and know their HIV status, to allow them to make informed decisions and choices. As such, the study data suggests that the highest number of respondents (31.3%) reported that they got tested because they, "*just wanted to know their status*". Other reasons cited for getting tested include, illness or death of partner or family member, suspected HIV related symptoms, pregnancy, and to a lesser extent other reasons included preparing for marriage or sexual partners or because of employment. The respondents also owned the decisions to get tested, with over half of the respondents citing that the decision to be tested for HIV was voluntary, while two fifths of the respondents also decided for themselves but due to pressure from others. It is against one's rights to be coerced into being tested for HIV, and while the percentage is low (2.4%), it is disturbing to note that some of the respondents had been coerced.

Through the VCT programs in the country, clients receive pre and post counselling testing, and this was evidenced by a high number (91%) of respondents who reported that they had received both pre - test and post - test counselling when they were undergoing HIV testing. With just

over 2% of the respondents being coerced and others being tested while they didn't know due to severe illnesses, it could be the reason why smaller percentages of the respondents either only got post-test counselling or did not receive any counselling when they had an HIV test.

4.1.7 Disclosure and Confidentiality

Largely, data suggests that people living with HIV and AIDS disclosed their status themselves without interference from a third party. The PLHIV largely disclosed their HIV status wilfully to their family members (children, spouses/partners, and other family members), other PLHIV, health care workers, counsellors and community members (friends and neighbours). To a lesser extent though they also disclosed their HIV status wilfully to community leaders, workmates (employers, clients and co-workers), religious leaders, and teachers.

At the point of disclosure, some spouses/partners and adult family members were reported to be very discriminatory, while on the other hand a higher number of the spouses/partners, the children, health care workers and counsellors among others were said to be very supportive. It must be noted however, that while people are at different levels, there are some elements who are still discriminatory, and as such more still needs to be done to address their attitudes.

4.1.8 Treatment

Zimbabwe has an ART program which is funded through the National AIDS Council whose aim is to reach universal access to ART to all PLHIV, and this is evidenced through the study data which suggests that most of the respondents were under ART treatment and when asked on their health status they reported that their health was either fair, good or excellent. As such HIV has taken a shift from the time when most PLHIV would be bed ridden, with most PLHIV now fit and strong and able to work for themselves. The GoZ and other non-state actors must be commended for their work with regards to the ART regime, as the study results revealed that all prison inmates reported that they have access to ART, with high percentages of MSM, Sex Workers and People with Disabilities reporting that they have access as well. However, efforts should be made to reach the remainder of those who report that they do not have access to ART.

4.1.9 Having children

As indicated in one section above, PLHIV need to make informed decisions and choices about their life, and this includes their reproductive options, and this study reveals that the respondents did access counselling about their reproductive options since they got diagnosed. Some (close to half) respondents were advised not to have children since they got diagnosed. However, it is also disturbing to note that while they are a few reported that they had been coerced you into being sterilised since you were diagnosed with HIV by a health professional.

4.2 Recommendations

To understand the ways in which HIV/AIDS-related Stigma and Discrimination appear and the contexts in which they occur, there is need to understand how they interact with pre-existing Stigma and Discrimination associated with sexuality, gender, race, and poverty among other things. It is essential to also consider that while Stigma and Discrimination are exerted on the individual by the outside world (family, community, workplace etc), one can experience self-stigma as a result of how they feel, and fears that they have which can be real or imagined. As such, this section seeks to proffer recommended actions to address HIV related Stigma and Discrimination:

- The starting point will be to ensure that the study findings are disseminated to relevant Government departments, The National AIDS Council, Donor Organisations, International

and Local CSOs involved in HIV programming, and the PLHIV through their organised structures (the Support Groups) and to the general public in Zimbabwe.

- Continuously raise awareness on the need for people to know their HIV status, and to also engage in community mobilisation programmes through community dialogues, sensitisation meetings and the use of edutainment (poetry, drama, music, sports etc.) to impart key messages that discourage HIV related stigma.
- It is also important to engage in targeted interventions to address various sources of stigma especially with regards to key populations who suffer double stigma as a result of either being sex workers, prison inmates, people with disabilities and men having sex with men who are living with HIV. It may be necessary to raise awareness at all levels starting from Government, Parliament and to the person in the street that PLHIV no matter their status for example of being a sex worker still have a right to live and to access services equitably.
- Promote and encourage disclosure of HIV status to spouse/partner and within families to foster forward planning.
- Lobby for health strengthening systems which increases reach and availability of required services such as ART, VCT and PMTCT among others to the remotest parts of the country.
- Educate and develop the capacity of health service providers to provide health services without discriminating against anyone on the basis of their HIV status, and provide the services equitably regardless of whether an individual is a sex worker or is LGBTI given that the laws of the country through the Public Health Act allows for the provision of services without discrimination.
- There is need to promote workplace stigma reduction efforts through the development and implementation of HIV-Stigma free work policies, developing the capacity of managers, supervisors, workplace peer educators and counsellors to provide accurate and adequate HIV information to their peers in the workplace.
- Nationally, it is important that the Government of Zimbabwe relooks at the labour laws and recruitment procedures which require applicants to get tested for HIV first, after which they may be discriminated against in terms of getting the job.
- The HIV epidemic has transformed, and it is important that at a national level players such as the National AIDS Council, the Zimbabwe National Network of People Living with HIV, The Zimbabwe AIDS Network among others transform the response to focus on availability, quality, and accessibility of services among other things. On the same note, it may be useful to consider supporting SRH and HIV linkages including integrating SRH issues for PLHIV into HIV programmes.
- The CSOs (NGOs and FBOs) and Networks involved in HIV programming need to organise themselves and articulate their issues with one voice, especially if they are going to influence national policy. PLHIV who are members of Support Groups should be organised as well so as to raise critical policy issues, which seek to protect the interests of PLHIV.
- The support group model has proven to be very useful in providing emotional support, HIV information and services to PLHIV, as such, it is key to continuously develop the capacity of the support groups, faith based organisations and other community based organisations to provide adequate counselling and other services.
- There is need to assess the role of players such as NAC, ZNNP, ZAN among others in reducing HIV related stigma and discrimination.

- Assess how effective NAC's Meaningful Involvement of PLHIV (MIPA) Programme has been in reducing HIV related stigma and how it has contributed to the empowerment of PLHIV.
- Evaluate the effectiveness of HIV in the Workplace Programmes that have been implemented by various players in the country.
- Include HIV related stigma and discrimination indicators as part of the National HIV Response M and E systems to monitor and evaluate progress over time.
- Females appear to be experiencing more stigma and discrimination compared to their male counterparts, and as such there is need to integrate gender equity and equality issues in HIV programming, especially with a focus to reducing stigma and discrimination.
- It is worthwhile for those involved in HIV programming to consider separating enacted and self-stigma. While there are many programs that focus on enacted stigma, there are few programs that have been put in place to address issues of self-stigma, and one such program in the Inquiry Based Stress Reduction (IBSR) Program which has already been piloted in Zimbabwe by Trocaire.

Through IBSR, PLHIV are trained on how to reduce their perceived level of stress through self-inquiry of their thoughts and beliefs connected to stressful circumstances or symptoms. The core of IBSR is simply four questions and a turnaround, which is a way of experiencing the opposite of what the participant believes. Using self-inquiry, PLHIV learn how to observe their emotional and physical responses during situations perceived by them as stressful and analyse negative thoughts and feelings. This enables women and men living with HIV to actively manage stressful thoughts and situations in a way that is positive and beneficial to their health and well-being.

4.3 Conclusion

Overall, the study suggests that while HIV programming in Zimbabwe has focused on HIV Prevention, Treatment Care and Support, there is still a gap with regards to HIV related stigma and discrimination. PLHIV still experience different forms of stigma and discrimination which include gossip, exclusion from social, religious and family activities, verbal and physical abuse among other things. HIV related stigma is reported to be still evident in the workplace, educational institutions, and also in the health institutions. However, there is evidence to show that some PLHIV suffer from self-stigma, which has affected the decisions and choices that they make. While HIV stigma and discrimination still needs to be addressed, it is commendable that Zimbabwe has made strides in terms of provision of services such as VCT, ART, PMTCT as evidenced by the number of people who reported to be on treatment, and also to have received pre and post-test counselling. In addressing HIV related stigma and discrimination, those responsible for HIV programming should consider addressing self-stigma, community mobilisation against stigma, lobbying for equitable health service provision, and lastly transforming the national response and working together to ensure that HIV related services are accessible, available and of an optimum required quality.

CHAPTER 5: APPENDICES**Appendix A: Focus Group Discussion Guide**

Focus Group Discussion Guide

ID	Beneficiaries FGD					
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Impact Research International**For****Zimbabwe Stigma Index Research****BENEFICIARIES FGD GUIDE**

1. Name of Health Care Facility(pre-complete)		
2. Name of District (pre-complete)		
5. Province (pre-complete)	Harare	1
	Mashonaland East	2
	Mutare	3
	Mashonaland Central	4
	Mashonaland West	5
	Bulawayo	6
	Midlands	7
	Masvingo	8
	Mat North	9
	Matebeleland South	10

FOR COMPLETION BY FGD MODERATOR	FGD Filename		
<i>Date:</i>	<i>DAY</i>	<i>MM</i>	<i>YY</i>
<i>Name of Moderator</i>			

Group Size	MALE		FEMALE	
Date of Quality Assurance (QC)	DAY	MM	YY	
Name of Quality Controller				
Name of Transcriber				
Date Transcribed	DAY	MM	YY	

INTRODUCTION

Good morning/afternoon. Thank you very much for coming to this group discussion meeting. My name is ___ and that of my colleague here is _____. I am representing a team of **Independent Consultants** who are working on the Zimbabwe Stigma Index Research.

Because we would like to ensure that no one can link your answers to you personally, **we will NOT write your name anywhere.** During data analysis, information from all respondents will be combined and analyzed together and the information that you will share with us will be treated confidentially.

We are interested in everyone's view – therefore, it is very important that, during the discussion, you all feel free to express your views, even if your views are different from others – it is normal for people to have different views on the issues we will be discussing.

Now, to make it easy to refer to each other during the discussion, **please think of a name(not your real name)** by which you would like to be called during this discussion – I will call myself _____, and I will stick that name on me (**as you do it**). Please do the same. (Hand out stickers for people to write their names or write the names on stickers for them.) (**WAIT UNTIL THIS IS COMPLETED BY EVERYONE**)

THE NEED FOR TAPE RECORDING AND GROUND RULES

- Explain that you will NEED TO record the discussion using a tape or digital recorder so that you can capture everything that is said. **{Obtain verbal consent} Once Consent is granted, TURN ON THE RECORDER at this point**

Before we begin, there are a few things which we must all follow, in order to have a meaningful discussion:

Because of the need to transcribe the recorded information later, it is important that only one person talks at a time, but one can kindly ask to respond while someone is still talking

Everyone must be allowed to express their views freely without being interrupted

At certain times, the note taker may need to check a point with the moderator, to make sure all questions are asked.

Explain that there are no right or wrong answers.

1. **[ICEBREAKER]** There are a lot of things people say about PLHIV. What do people in this community say about them?

2. Now let us talk about your own understanding of Stigma and Discrimination with regards to HIV/AIDS. In your view, what is HIV related stigma?

3. In your view, are PLHIV in this area **experiencing HIV related stigma**? YES/NO
If yes/no why?

4. Which group of people are mostly affected by HIV related stigma in your area?

Probe;

(Women, Children, Youth, Sex Workers, MSM, people living with Disabilities)

5. Now let us talk about the **forms of stigma and discrimination** of PLHIV in your area. In your view, what forms of HIV related stigma are prevalent in your area?

Probe;

- a. *Exclusion from community gatherings (e.g. weddings, funerals, parties, clubs)?*
- b. *Exclusion from religious activities or places of worship*
- c. *Exclusion from family activities (e.g. cooking, eating together, sleeping in the same room?)*
- d. *Exclusion from work related activities (employment, promotion, functions etc.)*
- e. *Gossiped about within the community*
- f. *Subjected to abuse (physical, verbal, psychological)*
- g. *Sexual rejection*

6. Now let us talk about your Knowledge on HIV related Stigma. Have you received any information on HIV related stigma in this Community?

Probes;

- a. Is there access to knowledge about adequate health facilities
- b. How much education have you received on reproduction and sexual health care?
- c. If so how effective and applicable has it been?

7. Now let us talk about the availability of **support structures** for victims of HIV related stigma. What support structures are there in this community to assist victims of HIV related stigma?

Probe;

- a. *When cases of stigma are reported, what processes do you follow to assist the victims?*
- b. *Give examples of stakeholders you work with to provide referrals for victims of HIV related stigma*

- c. *Do you think working with these stakeholders has been effective in reducing HIV related stigma?*
- d. *In terms of access to work as well as health facilities, are people living with HIV/AIDS receiving the same treatment as well as being given opportunities similar to people who are negative in this community?*

8. In your own views do you think PLHIV in this community are now comfortable or safe to disclose their status?

Probes;

- a. *If Yes/No. Why do you think are they comfortable or uncomfortable?*
- b. *What are the personal experiences you have personally had or witnessed within the society?*

9. Now let us talk about **policy considerations** for reducing HIV related stigma. Are you aware of any national policies that are in place to curb HIV related stigma?

Probe

- a. *Are the policies effective and applicable in addressing HIV related stigma in your area?*
- b. *Do you think there is need to change the policies, and if so what changes do you think should be made?*

10. We are now nearing to the end of our discussion (**Recommendations**). The views you have shared will be extremely useful to us. In your view what do you recommend that should be done to curb stigma and discrimination among the PLHIV

11. **Closure):** Is there anything else you would like us to know, which we did not talk about with regards to stigma and discrimination among think will PLHIV

Thank you very much for coming to this meeting and sharing your views with us.

ID	National Level Key Stakeholder IDI							

Impact Research International

For

Zimbabwe Stigma Index Research

KEY STAKEHOLDER INDEPTH INTERVIEW GUIDE

INTRODUCTION

Good day,

*My name is..... and I am from Impact Research International. We are a team of **Independent Consultants** who are working on the Zimbabwe Stigma Index Research. While participation in this study is voluntary, we would be grateful if you can take a few minutes of your time to share with me your thoughts and views.*

What you share with me will be treated confidentially and the results will be used only for the purposes of this study. During data analysis, information from all respondents will be combined and analysed together and nowhere in the report will we include participants' names.

We plan to record this interview, so that we capture everything that we will discuss today. If it is OK with you, I will turn on the recorder now.

Is that fine with you? *(Tick appropriate response)*

- Yes
- No

If no, we can still proceed but I will have to make detailed notes of our discussion as we go along.

1. Date of Key Stakeholder Discussion:	D	D	M	M	Y	Y
2. Interviewer Name:						
3. Name of note taker:						
4. Gender						

5. Key Stakeholder

Number:

6. Description of

Key Informant

1. **[ICEBREAKER]** What is your understanding on Stigma and Discrimination with regards to People Living with HIV?

2. Now let us talk about your **target population**. Which groups of people do you work with in your organisation?

Probe

(All PLHIV, PLHIV in churches, Sex Workers, MSM, Women, Youth, OVCs)

3. Now let us talk about the **types of stigma** that you have dealt with. What cases of stigma for PLHIV are commonly reported within your organisation?

Probe

- h. Exclusion from community gatherings (e.g. weddings, funerals, parties, clubs)?*
- i. Exclusion from religious activities or places of worship*
- j. Exclusion from family activities (e.g. cooking, eating together, sleeping in the same room?)*
- k. Exclusion from work related activities (employment, promotion, functions etc.)*
- l. Gossiped about within the community*
- m. Verbal abuse*

How did you address these reported cases?

4. What **policy considerations** do you make when addressing cases of stigma within your organisation?

Probe

- *National policies*
- *Organisational policies*

4a. Are these policies still applicable/ workable / effective in their current state?

4b. If these policies are to be amended, what do you think should be changed?

5. We are now nearing to the end of our discussion (**Recommendations**). The views you have shared will be extremely useful to us. In your view what do you recommend that should be done to curb stigma and discrimination among the PLHIV

6. **Closure):** Is there anything else you would like us to know, which we did not talk about with regards to stigma and discrimination among think will PLHIV

Thank you very much for coming to this meeting and sharing your views with us.

Appendix C: Community Level and District Key Informant Interview Guide

ID	District and Community Stakeholder IDI				
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Impact Research International

For

Zimbabwe Stigma Index Research

KEY STAKEHOLDER INDEPTH INTERVIEW GUIDE

INTRODUCTION

Good day,

*My name is..... and I am from Impact Research International. We are a team of **Independent Consultants** who are working on the Zimbabwe Stigma Index Research. While participation in this study is voluntary, we would be grateful if you can take a few minutes of your time to share with me your thoughts and views.*

What you share with me will be treated confidentially and the results will be used only for the purposes of this study. During data analysis, information from all respondents will be combined and analysed together and nowhere in the report will we include participants' names.

We plan to record this interview, so that we capture everything that we will discuss today. If it is OK with you, I will turn on the recorder now.

Is that fine with you? (Tick appropriate response)

- Yes
- No

If no, we can still proceed but I will have to make detailed notes of our discussion as we go along.

7. Date of Key Stakeholder Discussion:

D	D	M	M	Y	Y
---	---	---	---	---	---

8. Interviewer Name:

--

9. Name of note taker:

--

10. Province

--

11. District

--

12. Ward

--

13. Village/Suburb

--

14. Gender

--

15. Key Stakeholder

Number:

16. Description of

Key Informant

7. **[ICEBREAKER]** What is your understanding on Stigma and Discrimination with regards to People Living with HIV?

8. In your view, are PLHIV in this area **experiencing HIV related stigma**? YES/NO
If yes/no why?

9. Which group of people are mostly affected by HIV related stigma in your area?

Probe

(Women, Children, Youth, Sex Workers, MSM, people living with Disabilities)

10. Now let us talk about the availability of **support structures** for victims of HIV related stigma. What support structures are there in this community to assist victims of HIV related stigma?

Probe;

- e. *When cases of stigma are reported, what processes do you follow to assist the victims?*
- f. *Give examples of stakeholders you work with to provide referrals for victims of HIV related stigma*
- g. *Do you think working with these stakeholders has been effective in reducing HIV related stigma?*

11. Now let us talk about **policy considerations** for reducing HIV related stigma. Are you aware of any national policies that are in place to curb HIV related stigma?

Probe

- c. *Are the policies effective and applicable in addressing HIV related stigma in your area?*
- d. *Do you think there is need to change the policies, and if so what changes do you think should be made?*

12. We are now nearing to the end of our discussion (**Recommendations**). The views you have shared will be extremely useful to us. In your view what do you recommend that should be done to curb stigma and discrimination among the PLHIV

13. Closure): Is there anything else you would like us to know, which we did not talk about with regards to stigma and discrimination among think will PLHIV

Thank you very much for coming to this meeting and sharing your views with us.

Appendix D: Case Study Interview Guide

ID	Case Study					
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Impact Research International

For

Zimbabwe Stigma Index Research

KEY STAKEHOLDER INDEPTH INTERVIEW GUIDE

INTRODUCTION

Good day,

*My name is..... and I am from Impact Research International. We are a team of **Independent Consultants** who are working on the Zimbabwe Stigma Index Research. While participation in this study is voluntary, we would be grateful if you can take a few minutes of your time to share with me your thoughts and views.*

What you share with me will be treated confidentially and the results will be used only for the purposes of this study. During data analysis, information from all respondents will be combined and analysed together and nowhere in the report will we include participants' names.

We plan to record this interview, so that we capture everything that we will discuss today. If it is OK with you, I will turn on the recorder now.

Is that fine with you? (Tick appropriate response)

- Yes
- No

If no, we can still proceed but I will have to make detailed notes of our discussion as we go along.

1. Date of Case study Discussion:	D	D	M	M	Y	Y
2. Interviewer Name:						
3. Name of note taker:						
4. Age						
5. Gender						
6. Case Study Number:						
7. Description of Respondent						

1. ICEBREAKER: Following our discussion earlier on We saw it adequate that we have a one on one discussion in more detail.

To start with, would you like to tell me more about yourself and your status?

Probes;

- *How long have you been living positively with HIV/AIDS?*

- *What has been your experience?*
- *How did you disclose your status?*
- *How long did it take to disclose your status, and why?*
- *Reception from household, relatives, friends and community at large*
- *Why do you think people received it in that manner?*
- *Was there an available support system? If yes: (was it adequate or inadequate)*

2. **Now let us talk about the worst case of HIV related stigma that you experienced.** Would you like to narrate your worst case of HIV related stigma that you experienced from the time you started living with HIV.

Probes;

- *Description of the setting (household, workplace, church, health care facility, etc.)*
- *Description of the whole experience*

3. *Now let us talk about how you managed to deal with the situation. Who was there to support you during this time?*

Probes;

(Family, Friends, Relatives, Support Groups, other Community Based Organisations (CBOs), Faith Based Organisations (FBOs)

3a. ***Was there any change and how did you feel afterwards?***

4. In your own view what are the reasons why PLHIV are being discriminated against in this community. **If YES** outline the reasons. **If NO** explain why there are no people discriminated.
5. What do you think should be done in such circumstances and by whom?
6. **(Closure):** Is there anything else you would like us to know, which we did not talk about with regards to stigma and discrimination among think will PLHIV

Thank you very much for coming to this meeting and sharing your views with us.

Appendix E: Sampling Categories (Cluster A - J)

Cluster	Province	HIV Prevalence Rate % (ZDHS)	Weighting	n-values	Rounding off(n-values)
A	Mashonaland East	16	0.10062893 1	177.911949 7	178
B	Mashonaland West	15	0.09433962 3	166.792452 8	167
C	Mashonaland Central	14	0.08805031 4	155.672956	156
D	Manicaland	14	0.08805031 4	155.672956	156
E	Midlands	15	0.09433962 3	166.792452 8	167
F	Masvingo	14	0.08805031 4	155.672956	156
G	Matabeleland North	18	0.11320754 7	200.150943 4	200
H	Matabeleland South	21	0.13207547 2	233.509434	233
I	Harare	13	0.08176100 6	144.553459 1	144
J	Bulawayo	19	0.11949685 5	211.270440 3	211
		159		1768	1768

Appendix F: Sample Size Formulae

A technique called Probability proportional to size (Clusters) which is a multi-staged sampling technique was used. This is a multi staged sampling technique. In this technique the whole country was clustered into 10 provinces which were the 10 clusters.

The ZDHS informed the researchers on the HIV prevalence rate per province. This was used for weighting purposes.

The formula below was used,

$$n = D [Z_a (2P (1 - P))^{1/2} + Z_b (P_1 (1 - P_1) + P_2 (1 - P_2))^{1/2}]^2 / (P_2 - P_1)^2$$

Where:

D = design effect;

Z_a = the z-score corresponding to the probability with which it is desired to be able to conclude that an observed change of size (P₂ - P₁) would not have occurred by chance;

$$P = (P_1 + P_2) / 2;$$

Z_b = the z-score corresponding to the degree of confidence with which it is desired to be certain of detecting a change of size (P₂ - P₁), if one actually occurred.

P₁ = the estimated proportion at the time of the first survey; and

P₂ = the proportion at some future date such that the quantity (P₂ - P₁) is the size of the magnitude of change it is desired to be able to detect;

Assumptions

D=2, P1=0.5, P2=0.5, Zalpha=1.96 and Zbeta=1.645

Appendix G: Sampling Frame

Province	Districts	n-value per province	n-value per district	n-value/district rounded off
Manicaland(10)	Buhera	156	15.6	16
	Chimanimani		15.6	16
	Chipinge Rural		15.6	16
	Chipinge Urban		15.6	16
	Makoni		15.6	16
	Mutare Rural		15.6	16
	Mutare Urban		15.6	16
	Mutasa		15.6	16
	Rusape Urban		15.6	16
	Nyanga		15.6	16
Mashonaland Central(10)	Bindura Rural	156	15.6	16
	Bindura Urban		15.6	16
	Guruve		15.6	16
	Mazowe		15.6	16
	Mbire		15.6	16
	Mount Darwin		15.6	16
	Muzarabani		15.6	16
	Mvurwi		15.6	16
	Rushinga		15.6	16
	Shamva		15.6	16
	Mashonaland East(11)		Chikomba	178
Goromonzi		16.18181818	16	

	Hwedza		16.18181818	16
	Marondera Rural		16.18181818	16
	Marondera Urban		16.18181818	16
	Mudzi		16.18181818	16
	Murehwa		16.18181818	16
	Mutoko		16.18181818	16
	Seke		16.18181818	16
	UzumbaMaramba Pfungwe		16.18181818	16
	Ruwa		16.18181818	16
Mashonaland West(13)	Chegutu Rural	167	12.84615385	13
	Chegutu Urban		12.84615385	13
	Chinhoyi		12.84615385	13
	Hurungwe		12.84615385	13
	Kadoma Urban		12.84615385	13
	Kariba Rural		12.84615385	13
	Kariba Urban		12.84615385	13
	Karoi		12.84615385	13
	Makonde		12.84615385	13
	Mhondoro-Ngezi		12.84615385	13
	Norton		12.84615385	13
	Sanyati		12.84615385	13
	Zvimba		12.84615385	13
Masvingo(9)	Bikita	156	17.33333333	17
	Chiredzi Rural		17.33333333	17
	Chiredzi Town		17.33333333	17
	Chivi		17.33333333	17
	Gutu		17.33333333	17
	Masvingo Rural		17.33333333	17
	Masvingo Urban		17.33333333	17
	Mwenezi		17.33333333	17
	Zaka		17.33333333	17
Matebeleland North(9)	Binga	200	22.22222222	22
	Bubi		22.22222222	22
	Hwange Rural		22.22222222	22
	Hwange Urban		22.22222222	22
	Lupane		22.22222222	22
	Nkayi		22.22222222	22
	Tsholotsho		22.22222222	22
	Umguzha		22.22222222	22
	Victoria falls		22.22222222	22
Matebeleland South(10)	Beitbridge Rural	233	23.3	23

	Beitbridge Urban		23.3	23
	Bulilima		23.3	23
	Mangwe Rural		23.3	23
	Mangwe Urban (Plumtree)		23.3	23
	Gwanda Rural		23.3	23
	Gwanda Urban		23.3	23
	Insiza		23.3	23
	Matobo		23.3	23
	Umzingwane		23.3	23
Midlands(14)	Chirumhanzu	167	11.92857143	12
	Gokwe Centre		11.92857143	12
	Gokwe North		11.92857143	12
	Gokwe South		11.92857143	12
	Gweru Rural		11.92857143	12
	Gweru Urban		11.92857143	12
	Kwekwe Rural		11.92857143	12
	Kwekwe Urban		11.92857143	12
	Mberengwa		11.92857143	12
	Redcliff		11.92857143	12
	Shurugwi Rural		11.92857143	12
	Shurgwi Urban		11.92857143	12
	Zvishavane Rural		11.92857143	12
	Zvishavane Urban		11.92857143	12
Harare(4)	Harare Rural	144	36	36
	Harare Urban		36	36
	Epworth		36	36
	Highfield		36	36
Bulawayo(1)	Bulawayo Urban	211	211	211
				1769

IRI Supervisors: Mrs S Chitekuteku (Northern Region) and Mr C Mandizvidza (Southern Region)

Appendix J: Informed Consent Form



INFORMED CONSENT FORM

To be completed by the interviewee and the interviewer.

My name is.....

[INSERT the name of the interviewer.]

I am administering a questionnaire about the experiences of people living with HIV, particularly the experiences of stigma and discrimination they may have had.

I have provided you with an information sheet that describes the purpose of this questionnaire and how the information collected from this questionnaire will form part of a larger survey that is being conducted in this country to document some of the experiences of people living with HIV. The information sheet also outlined what types of information you will be asked, how we will keep this information confidential and the potential risks involved in your participating in this survey.

Before we begin the questionnaire, I would like to make sure that you are voluntarily willing to participate in this survey and that you have obtained all the information that you need in order to make an informed choice about your participation.

This consent form may contain words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain. You do not have to decide today whether or not you will respond to this questionnaire. Before you make a decision, you can talk to anyone you feel comfortable with about the questionnaire and/or the survey.

Please feel free to also contact the project team leader if you have any questions or

concerns about this questionnaire or the survey. These are the contact details for the team leader:

Name.....
.....

Contact
details.....
.....
.....

[INSERT the name of the team leader plus appropriate contact details such as their telephone number(s), email address and their physical address.]

If, however, you choose to respond to this questionnaire and thus participate in the survey, I will ask you some questions about some of your experiences as a person living with HIV, in particular those related to the experiences of stigma or discrimination you may have had. I expect that the interview will take between two and three hours.

Before asking you whether or not you would like to be a participant, I would like you to know that:

1. Your participation in this survey is entirely voluntary. It is your choice whether to participate or not.
2. You are free to not answer any of the questions in the questionnaire.
3. You may stop participating in the interview at any time that you wish.

The information collected in this interview will be kept strictly confidential. To help ensure confidentiality, I will not write your name on the questionnaire or this form, and I will not write down particular details that would allow you to be identified. If you would like to know more about the measures that we are taking to protect confidentiality, please ask me to provide you with these details. Your participation will include my providing you with a list of services that are available in our community, including health care, social support and legal services.

Do you consent to participating in the interview?

Yes 1

No 2

If **NO**: Thank you for your time.

If **YES**: Thank you for agreeing to take part in this project.

By saying yes, that means that you have read the information on the information sheet, or it has been read to you. You have had the opportunity to ask questions related to the questionnaire and the People Living with HIV Stigma Index survey and any questions you have asked have been answered to your satisfaction. You consent voluntarily to be a

participant in this project and you understand that you have the right to end the interview at any time.

If you agree, I will now sign this form to confirm that your consent has been obtained

Signature/initials of interviewer.....

Date of interview

Your verbal consent is all that is needed to go ahead with the interview. If you feel comfortable enough doing so, however, you can also sign your name or initials below to indicate that you have consented in writing to participating in this interview.

However, please remember that verbal consent is all that is needed. You do not have to provide us with written consent, but you can if you would like to.

I have read the information on the information sheet, or it has been read to me. I have had the opportunity to ask questions related to the questionnaire and the People Living with HIV Stigma Index survey, and any questions I have asked have been answered to my satisfaction. I consent voluntarily to be a participant in this project and understand that I have the right to end the interview at any time.

Signature/initials of interviewee.....

Date of interview.....

Appendix K: Study Provinces and Districts

Province	District
Masvingo	Zaka
	Bikita
	Chivi
Harare	Epworth
	Mbare
	Chikurubhi
	Zengeza
	Harare Metropolitan
Matebeleland South	Gwanda
	Umzingwane
Mashonaland West	Zvimba
	Makonde
	Hurungwe
Bulawayo	Magwegwe
	Nkulumane
	North end
Manicaland	Makoni
	Mutasa
Mashonaland Central	Mazowe
	Mount Darwin
Matebeleland North	Lupane
	Khami Prison
	Tsholotsho
Mashonaland East	Wedza
	Marondera
Midlands	Zvishavane
	Kwekwe
	Gweru Urban

Appendix L: MRCZ Letters of Approval

Telephone: 791792/791193
 Telefax: (263) - 4 - 790715
 E-mail: mrcz@mrcz.org.zw
 Website: <http://www.mrcz.org.zw>



Medical Research Council of Zimbabwe
 Josiah Tongogara / Mazoe Street
 P. O. Box CY 573
 Causeway
 Harare

APPROVAL

Ref: MRCZ/A/1782

24 October, 2013

Professor Patrick Chiroro
 University of Durham (UK)
 10 Clara Road
 Marlborough
Harare

RE:- To carry out a research process for the Stigma Index for Zimbabwe

Thank you for the above titled proposal that you submitted to the Medical Research Council of Zimbabwe (MRCZ) for review. Please be advised that the Medical Research Council of Zimbabwe has **reviewed** and **approved** your application to conduct the above titled study. This is based on the following documents that were submitted to the MRCZ for review:

- Research Protocol
- Informed Consent Form (English and Shona)
- Information Sheet (English and Shona)

• **APPROVAL NUMBER** : MRCZ/A/1782

This number should be used on all correspondence, consent forms and documents as appropriate.

- **TYPE OF REVIEW** : Expedited
- **EFFECTIVE APPROVAL DATE** : 24 October 2013
- **EXPIRATION DATE** : 23 October 2014

After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the MRCZ Website should be submitted three months before the expiration date for continuing review.

- **SERIOUS ADVERSE EVENT REPORTING:** All serious problems having to do with subject safety must be reported to the Institutional Ethical Review Committee (IERC) as well as the MRCZ within 3 working days using standard forms obtainable from the MRCZ Website.
- **MODIFICATIONS:** Prior MRCZ and IERC approval using standard forms obtainable from the MRCZ Website is required before implementing any changes in the Protocol (including changes in the consent documents).
- **TERMINATION OF STUDY:** On termination of a study, a report has to be submitted to the MRCZ using standard forms obtainable from the MRCZ Website.
- **QUESTIONS:** Please contact the MRCZ on Telephone No. (04) 791792, 791193 or by e-mail on mrcz@mrcz.org.zw
- **Other**
- Please be reminded to send in copies of your research results for our records as well as for Health Research Database.
- You're also encouraged to submit electronic copies of your publications in peer-reviewed journals that may emanate from this study.

Yours Faithfully

.....

**MRCZ SECRETARIAT
 FOR CHAIRPERSON
 MEDICAL RESEARCH COUNCIL OF ZIMBABWE**



Telephone: 791792/791193
 Telefax: (263) - 4 - 790715
 E-mail: mrcz@mrcz.org.zw
 Website: <http://www.mrcz.org.zw>



Medical Research Council of Zimbabwe
 Josiah Tongogara / Mazoe Street
 P. O. Box CY 573
 Causeway
 Harare

CONTINUING REVIEW APPROVAL LETTER

Ref: MRCZ/A/1782

20 October, 2014

Professor Patrick Chiroro
 Impact Research International
 Clara Road
 New Marlborough
Harare

RE:- Zimbabwe Stigma Index Research

Thank you for the application for approval to continue carrying out research activity that you submitted for review to the Medical Research Council of Zimbabwe (MRCZ). Please be advised that the Medical Research Council of Zimbabwe has **reviewed** and **approved** your application to continue conducting the above titled study.

This approval is based on:-

- a) Completed MRCZ Continuing review Application Form
- b) Progress report

- **APPROVAL NUMBER** : MRCZ/A/1782

This number should be used on all correspondence, consent forms and documents as appropriate.

- **EFFECTIVE APPROVAL DATE** : 24 October, 2014
- **EXPIRATION DATE** : 23 October, 2015
- **TYPE OF MEETING** : Full Board

After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the MRCZ Offices should be submitted one month before the expiration date for continuing review.

- **SERIOUS ADVERSE EVENT REPORTING:** All serious problems having to do with subject safety must be reported to the Institutional Ethical Review Committee (IERC) as well as the MRCZ within 3 working days using standard forms obtainable from the MRCZ Offices.
- **MODIFICATIONS:** Prior MRCZ and IERC approval using standard forms obtainable from the MRCZ Offices is required before implementing any changes in the Protocol (including changes in the consent documents).
- **TERMINATION OF STUDY:** On termination of a study, a report has to be submitted to the MRCZ using standard forms obtainable from the MRCZ Offices.
- **QUESTIONS:** Please contact the MRCZ on Telephone No. (04) 791792, 791193 or by e-mail on mrcz@mrczimshared.co.zw.

Other

- Please be reminded to send in copies of your research results for our records as well as for Health Research Database.
- You're also encouraged to submit electronic copies of your publications in peer-reviewed journals that may emanate from this study.

Yours Faithfully

MRCZ SECRETARIAT
 FOR CHAIRPERSON
 MEDICAL RESEARCH COUNCIL OF ZIMBABWE



