



# **PEOPLE LIVING WITH HIV STIGMA INDEX 2.0**

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**Zambia – 2023**



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## FOREWORD

In a world striving for progress, compassion and understanding, the persistence of stigma remains a profoundly troubling barrier to attaining universal wellbeing and parity. The Stigma Index, a reflection of both the obstacles we confront and the progress we must make, is a crucial instrument for unravelling the complex stigma threads that continue to entangle our societies.

Stigma, which is frequently anchored in ignorance and fear, can have a significant impact on individuals and communities. It manifests in innumerable ways, marginalising those who may already be vulnerable due to their health, identity or other circumstances. The Stigma Index is a lighthouse that illuminates these shadowy corners of society, allowing us to better understand the dynamics of stigma and its far-reaching effects.

This exhaustive effort not only explores the lived experiences of those burdened by stigma but also serves as a wake-up call for all of us to challenge and transform our attitudes and perceptions. The Stigma Index humanises the statistics by illuminating the stories of resilience and vulnerability and confronts us with the urgency of change. It contains the narratives of individuals who have confronted prejudice head-on and emerged as champions for their own dignity and rights. Their journeys inspire us to create a world where comprehension and compassion triumph over ignorance and prejudice. The Stigma Index not only identifies the problems but also highlights the potential for progress based on empathy, solidarity and empirical action.

As we examine the findings presented in the Stigma Index, let us keep in mind that stigma is not an isolated problem but rather a web whose threads weave across societies, affecting health, relationships and opportunities. By recognising its existence and repercussions, we pave the way for meaningful dialogue, policy changes and collective efforts that can reshape the landscape of human dignity.

May this index serve as a catalyst for self-reflection and action, propelling us towards a future where stigma holds no sway and every person is valued, respected and supported. Let us embark together on this journey towards a more compassionate world, one that recognises our shared humanity and removes the obstacles that prevent us from realising our maximum potential.



Prof Lloyd Mulenga

**Acting Director General**

**NATIONAL HIV/STI/TB COUNCIL**

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## ACKNOWLEDGEMENTS

I applaud the tireless efforts of everyone who was involved in the establishment of the Stigma Index. Your commitment to truth, comprehension and inclusiveness exemplifies the strength of collaboration and the potential for positive change.

I would like to take this opportunity to extend my heartfelt gratitude to our esteemed partners for their unwavering support throughout the execution of the PLHIV Stigma Index 2.0.

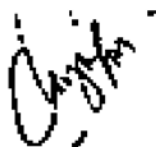
First and foremost, I would like to thank the Ministry of Health, and the National AIDS Council, for their invaluable financial backing that facilitated the implementation of the Stigma Index. This generous financial support enabled us to convene essential technical committee meetings, facilitate data collection, engage a proficient consultant and appoint a dedicated study coordinator.

Secondly, I would like to take this opportunity to convey my profound gratitude to the members of the Steering and Technical Committees. Their technical expertise has been instrumental in shaping the direction of the study and has greatly enriched the outcome of this project. I also extend my specific acknowledgment to the Global Network of People Living with HIV (GNP+) and UNAIDS for their invaluable technical guidance and mentorship and their support empowered and capacitated NZP+, allowing us to spearhead the roll-out of the Zambia PLHIV Stigma Index 2.0. GNP+ provided indispensable resources, including the PLHIV Stigma Index Implementation Guidelines, standardised questionnaire and other tools and templates that constitute the bedrock of the PLHIV Stigma Index 2.0 and reviewed every step of the Stigma Index implementation process.

My sincere gratitude extends to the dedicated research assistants and community liaison officers whose commitment was vital throughout the research process. I also wish to acknowledge the essential role played by individuals living with HIV who participated in the research. Their experiences and insights informed the findings of the study and I trust that these findings will play a pivotal role in enhancing the health and overall quality of life for both individuals living with HIV and the broader affected communities.

Lastly, my special recognition goes to the diligent staff and management of the NZP+ secretariat. Their unwavering commitment and seamless collaboration with the research consultant, study coordinator and technical team have been integral to the success of the study. I would also like to extend our appreciation to the consultant, from the University of Zambia, for his expert guidance and patience spanning from protocol development to the finalisation of this comprehensive report.

NZP+ stands truly humbled and profoundly thankful for the collective efforts of our partners and collaborators. It is through this synergy that we envision a future marked by reduced stigma and improved well-being for all individuals living with HIV and the communities.



Fred Misumbi Chungu

**Executive Director**

**NETWORK OF ZAMBIAN PEOPLE LIVING WITH HIV AND AIDS (NZP+)**

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## LIST OF ABBREVIATIONS

|         |                                                    |
|---------|----------------------------------------------------|
| AIDS    | Acquired Immunodeficiency Syndrome                 |
| ART     | Antiretroviral Therapy                             |
| CHAI    | Clinton Health Access Initiative                   |
| CHAZ    | Churches Health Association of Zambia              |
| CSOs    | Civil Society Organisations                        |
| FSW     | Female Sex Workers                                 |
| GIPA    | Greater Involvement of People living with HIV      |
| GNP+    | Global Network of People Living with HIV           |
| HCT     | HIV Counselling and Testing                        |
| HIV     | Human Immunodeficiency Virus                       |
| HTC     | HIV Testing and Counselling                        |
| ICW     | International Community of Women Living with HIV   |
| IPPF    | International Planned Parenthood Federation        |
| KP      | Key Populations                                    |
| MoH     | Ministry of Health                                 |
| MSM     | Men who have Sex with Men                          |
| NAC     | National HIV/AIDS/STI/TB Council                   |
| NGOs    | Non-Governmental Organisations                     |
| NHRA    | National Health Research Authority                 |
| NZP+    | Network of Zambian people living with HIV          |
| PEPFAR  | President's Emergency Plan for AIDS Relief         |
| PLHIV   | People Living with HIV                             |
| SAT     | Sexual Reproductive Health and Rights Africa Trust |
| SW      | Sex Workers                                        |
| TALC    | Treatment Advocacy and Literacy Campaign           |
| TG      | Transgender                                        |
| UNAIDS  | Joint United Nations Programme on HIV and AIDS     |
| UNICEF  | United Nations Children's Fund                     |
| ZAMPHIA | Zambia Population-based HIV Impact Assessment      |
| ZAMSTAT | Zambia Statistics Agency                           |
| ZDHS    | Zambia Demographic and Health Survey               |

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## KEY TERMS AND DEFINITIONS

|                                |                                                                                                                                                                                                                                                                                                                                                                                        |
|--------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Key Population:</b>         | This term applies to men who have sex with men, transgender individuals, sex workers, people who inject drugs (PWID) and people in prisons and other closed settings. In the framework of PLHIV Stigma Index 2.0 the term applies to: men who have sex with men and other gay men, sex workers of all genders, people who use and inject drugs of all genders and transgender persons. |
| <b>Discrimination:</b>         | Refers to prejudiced and unfair treatment of others based on such characteristics as age, gender, race, ethnicity or sexual orientation.                                                                                                                                                                                                                                               |
| <b>External/Public Stigma:</b> | Refers to negative or discriminatory beliefs, behaviours and attitudes that others have about people living with HIV.                                                                                                                                                                                                                                                                  |
| <b>Internalised Stigma:</b>    | Often refers to the negative or discriminatory attitudes that people living with HIV have about themselves.                                                                                                                                                                                                                                                                            |
| <b>Institutional Stigma:</b>   | Refers to the more systemic forms of discrimination involving the government or other official policies that portray people living with HIV negatively and limit their opportunities whether intentionally or unintentionally. This may include such actions as underfunding HIV related programmes.                                                                                   |

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## EXECUTIVE SUMMARY

This report presents the findings of the People Living with HIV (PLHIV) Stigma Index 2.0 study of Zambia. The Stigma Index is a standardised research programme, conducted by and for people living with HIV, with the aim of documenting the experiences of people living with HIV in all their diversity with stigma and discrimination. The Stigma Index has been implemented in Zambia once before, in 2012. The objective was to gather evidence on the stigma and discrimination experienced by PLHIV to advocate for change. This executive summary provides a brief overview of the key findings of this study.

In terms of the methodology, all PLHIV Stigma Index implementations make use of the standardised Stigma Index 2.0 questionnaire, which is quantitative in nature and is implemented following a rigorous standardised methodology. This study, however, utilised a mixed-methods design, integrating this instrument with an exploratory qualitative case study approach. The study was carried out in 25 (out of 116) districts across Zambia's 10 provinces, selected based on several criteria such as HIV prevalence rates (including both low and high prevalence areas) and societal attitudes. This comprehensive approach aimed to construct a national profile of stigma experiences, accounting for both population size and prevalence distribution. It also ensured representation across diverse HIV prevalence regions, thereby mitigating potential biases toward larger population or urban districts. The quantitative sample consisted of 2, 007 participants, recruited via venue-based sampling and limited-chain referral sampling approaches. The qualitative sample included 60 participants, who were selected through purposive sampling. Data collection took place in March and April 2023. Quantitative data were analysed using Stata 22 and qualitative interviews were analysed through NVivo 12.0.

Of all the 2, 007 participants, 61.3 per cent (n=1, 228) were assigned female at birth and 38.7 per cent (n=775) were assigned male at birth. Regarding their current gender identity, 60.6 per cent of participants identified themselves as female; 35.4 per cent as male; 3.5 per cent as transgender; 0.2 per cent did not identify as female, male or transgender; and 0.2 per cent opted not to respond. Participant ages ranged between 18 and 73 years, with almost half of the participants (45.5%) being 40 years or older. On average, participants had been aware of their HIV status for 8.9 years, with the longest duration being 38 years. A vast majority of the participants (68.1%) has been aware of their HIV status for more than 4 years. Many participants (41.9%) indicated to be unemployed. Some participants indicated to be unable to meet their basic needs sometimes (68.3%) or most of the time (21.2%). The findings also revealed low participation in support groups, with 61.8 per cent of the sample (n=1, 238) not being affiliated to a network or support group for PLHIV.

Findings showed that disclosure of HIV status without consent is most prevalent among individuals aged 18-19 years (31.0%) and people who use drugs (46.0%). In addition, most participants (65.5%) stated that they generally do not disclose their HIV status when seeking general (non-HIV related) health services. Most participants (62.5%) agreed with the statement that people they were close to were supportive when first learning about their HIV status, while only 16.1 per cent of the participants agreed that people that they did not know very well were supportive.

With regards to external stigma and discrimination, participants were asked about different types of experiences with external stigma and discrimination because of their HIV status. Within the last 12 months, 29.1 per cent of the participants reported having had at least one such experience, while 51.7 per cent reported having ever had such encounters. A closer examination of key populations unveils distinct disparities: 61.8 per cent of gay men and other MSM; 70.7 per cent of sex workers; 78.3 per cent of PWUD; and 68.1 per cent of transgender individuals indicated facing external stigma and discrimination. In comparison, 44.3 per cent of non-key population participants reported similar encounters. Regarding experiences of stigma and discrimination for reasons other than HIV status, there are variations in KP groups, with 12 per cent of transgender people; 14.9 per cent of

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MSM; 34.6 per cent of sex workers; and 40.6 per cent of PWUD indicated facing exclusion from family activities due to being part of a key population.

In terms of internalised stigma, a relatively larger proportion of participants reported experiencing internalised stigma compared to external stigma. Analysis covered emotional aspects, such as self-confidence; self-respect; the ability to respect others; capacity to cope with stress; and the capacity to form romantic relationships. The analysis also examined behavioural manifestations like avoidance of social gatherings; reluctance to seek employment; hesitancy in seeking social support; and abstaining from sex, due to the HIV status.

Generally, 32.2 per cent of the participants acknowledged having undertaken at least one of the specified actions and 65.5 per cent agreed with at least one of the statements delineating their emotional experiences related to internalised stigma. Both actions and feelings associated with internalised stigma reduced with increasing age, suggesting that internalised stigma is more prevalent among younger individuals. People who had taken actions or experienced feelings related to internalised stigma were more likely to interrupt or discontinue their HIV treatment.

The study found that 59.1 per cent of those who had taken actions related to internalised stigma had, at some point, interrupted or stopped their HIV treatment, compared to 23.6 per cent among those who did not take such actions. Similarly, 82.3 per cent of individuals who reported experiencing feelings associated with internalised stigma had, at some point, interrupted or stopped their HIV treatment, compared to 59.6 per cent among those who did not encounter such feelings. These findings underscore the significance of addressing internalised stigma, particularly among younger populations, and its potential impact on HIV treatment adherence and continuity.

Besides HIV-related internalised stigma, the study also found disparities in the fear of seeking health services among key populations. Specifically, 38.7 per cent of PWUD, 28.5 per cent of sex workers and 25.2 per cent of MSM expressed concerns about seeking health services due to the fear of stigma and discrimination, in contrast to 10.6 per cent of transgender individuals who reported similar apprehensions. Experiences of blackmail were more prevalent among PWUD, with 30.2 per cent reporting such instances.

In terms of HIV testing, care, treatment and service delivery experiences, the findings show that 90.0 per cent of participants were either currently receiving or had ever received HIV treatment. Most participants (80.9%) sought HIV care and treatment at government clinics, followed by 11.4 per cent who received their HIV care and treatment at non-governmental clinics. Treatment interruptions were most prevalent among individuals aged between 20-24 (27.3%) and those aged 25-30 (27.6%). The interruptions were influenced by nuanced barriers related to internalised stigma. For instance, the qualitative study results revealed that some individuals interrupted their care while awaiting injectable medications; to avoid being recognised by others; or to avoid being associated with daily oral tablets. Additionally, concerns regarding societal attitudes towards MSM prompted some individuals to seek treatment in distant locations, where they could avoid potential stigma, despite the logistical challenges of transportation.

With regards to sexual and reproductive health, the study observed that participants had received some specific advice regarding their sexual and reproductive health from health care workers due to their HIV status. For example, 2.5 per cent of the participants indicated that they had been advised not to mother or father a child and 0.8 per cent reported that they had been pressurised or incentivised to get sterilised. In addition, 1.6 per cent had been told they had to use a specific method of contraception to get their HIV treatment. Similarly, among participants who were assigned female at birth, results showed that those in age group 30 to 34 years were the most affected by such treatment.

In terms of human rights and affecting change, participants were asked about their knowledge of laws safeguarding people living with HIV from stigma and discrimination in Zambia. Over half (54.1%) of participants were aware of the existence of national laws that protect PLHIV from

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stigma and discrimination, while 3.8 per cent stated there were no such laws and 42.1 per cent did not know if there were laws that protected PLHIV from stigma and discrimination. Regarding experiences of forced testing for HIV or disclosure of their status, no major differences in sex at birth were observed, while those part of a key population and those aged 25-29 years indicated that they had more often experienced at least one of the rights abuses asked about. The participants were also asked about any actions they have taken to affect change in relation to stigma and discrimination. Actions most often taken by the participants were challenging or educating someone who was engaging in stigma and discrimination against other people living with HIV (56.1%), followed by providing emotional, financial or other support to help someone living with HIV deal with stigma and/or discrimination (53.4%).

It can be concluded that this study provides evidence on stigma and discrimination among people living with HIV in Zambia. The findings of the study show the persistence of both internalised and external stigma and discrimination related to HIV, with key populations facing higher levels of discrimination. In addition, the study observed high levels of internalised stigma, particularly among younger individuals, which can have a significant impact on HIV treatment adherence. The findings indicate that most participants are engaged in HIV treatment, mainly at government clinics, although treatment interruptions are still prevalent. Such interruptions can be influenced by many factors, including internalised stigma. The report also highlights concerns about the advice given by the healthcare workers when it comes to sexual and reproductive health. Participants indicated experiences of reproductive coercion.

In summary, this study underscores the urgency of addressing stigma, both external and internalised. This is to enhance the well-being of all people living with HIV. It calls for targeted interventions; awareness campaigns; and support systems, to improve HIV treatment adherence and foster a more inclusive and supportive environment for people living with HIV in Zambia. Based on the evidence collected by this study, the recommendation on fostering collaboration and partnerships between government agencies, civil society organisations, healthcare providers and community-based organisations to leverage strengths, resources and expertise to address access barriers and improve the overall HIV response, resonates well in calling on all stakeholders for a collaborative, targeted approach to reduce stigma and discrimination experienced by PLHIV in all their diversity.



## 1.0 INTRODUCTION

### 1.1 Background

HIV remains a major problem in Zambia. Zambia had close to 1.2 million people living with HIV (PLHIV) according to the Zambia Demographic and Health Survey (ZDHS) of 2018.<sup>1</sup> The national HIV prevalence among the population aged 15 to 49 years is at 11.1 per cent. However, women continue to be disproportionately affected. The ZDHS shows that the HIV prevalence was higher among women aged 15-49 years (15.1%) compared to men in the same age group (11.3%).<sup>2</sup> The adult prevalence rate among people aged 15 - 49 years was greater than five per cent in all 116 districts. The country fact sheet by UNAIDS currently estimates the total population of people living with HIV to be between 1,300,000 and 1,400,000.<sup>3</sup> These estimates also suggest that the prevalence rate among men is 7.7 per cent compared to 13.8 per cent among women between the ages of 15 and 49 years. Evidence suggests that HIV prevalence generally increases with age groups, rising from 2.6 per cent in women aged 15 to 19 years to 22.7 per cent in women aged 45 to 49 years, and from 1.2 per cent in males aged 15 to 19 years to 17.0 per cent in men aged 45 to 49 years. Young people (between 15 and 24 years old) are the most represented in the burden of new infections. Although they account for 20 per cent of the entire population, they make up 40 per cent of all new HIV infections. In addition, available estimates from 2020 show that HIV rates among key populations in Zambia are high as shown in table 1.

**Table 1: Table 1: Key population HIV prevalence estimates**

| Key Population        | Total Population | HIV Prevalence (%) | Estimated total PLHIV |
|-----------------------|------------------|--------------------|-----------------------|
| Gay men and other MSM | 128,053          | 21%                | 26,891                |
| Sex workers           | 142,725          | 40%                | 57,090                |
| PWUD                  | 26,840           | 15%                | 4,026                 |
| Transgender people    | 11,435           | 22%                | 2,516                 |
| Total                 | 309,053          | 29.3%              | 90,523                |

Source: UNAIDS 2020

According to the Zambia Population-based HIV Impact Assessment (ZAMPHIA)<sup>4</sup> as of 2016, the yearly HIV incidence rate among adults aged 15-59 years in Zambia was 0.61 per cent (0.29 per cent among males and 0.93 per cent among females). This equates to around 43,000 new HIV cases each year among individuals in Zambia aged 15-59 years. The 2020 Spectrum estimates<sup>5</sup>, on the other hand, indicate that new HIV infections were 43,000 in 2016 and 38,000 in 2021. Zambia's Prevention Road Map<sup>6</sup> Target by 2020 was to reduce new infections down to at least 12,500 new infections.

Another key aspect of HIV prevalence in Zambia is its unequal spatial distribution. Urban areas have higher prevalence by residence (15.9%) compared to rural areas (7.1%). Of the ten provinces, the Copperbelt province has the highest prevalence at 15.4 per cent while Muchinga is lowest at 5.4 per cent. According to the Ministry of Health, Zambia has made progress across the HIV treatment

<sup>1</sup> Zambia Demographic Health Survey. 2018. Central Statistics Office, GRZ.

<sup>2</sup> Zambia Demographic Health Survey. 2014. Central Statistics Office, GRZ.

<sup>3</sup> <https://www.unaids.org/en/regionscountries/countries/zambia>

<sup>4</sup> Zambia Population Based Impact Assessment 2016. Zambia Statistics Agency, GRZ.

<sup>5</sup> UNAIDS, Zambia Country Spectrum Estimates 2020.

<sup>6</sup> Zambia Prevention Road Map.

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cascade for adults. On the 95-95-95 targets, the country has reached 94.7- 95.1- 94.6 for adults in HMIS 2020.<sup>10</sup>

Given the above country situation, issues of stigma and discrimination against people living with HIV become critical to intervention efforts. Stigma has been defined as a deeply discrediting attribute, a mark of shame or oppression, which translates into difference, which in itself communicates devaluation.<sup>7</sup> However, discrimination entails the negative effects of stigma. It is underpinned by prejudice and involves policies, practices and attitudes often carried by more powerful groups to disadvantage others based on their membership of a certain group.<sup>8</sup> Widespread stigma and discrimination within a population has a detrimental effect on people's health seeking behaviour, including on testing and adherence to antiretroviral therapy (ART). HIV-related stigma and discrimination refer to prejudice, negative attitudes and abuse directed at people living with HIV. In 35 per cent of countries where data is available, over 50 per cent of the people are reported to have discriminatory attitudes towards PLHIV.<sup>9</sup>

Stigma and discrimination also affect the mental health and wellbeing of people with HIV. Those most at risk of HIV (key affected populations) continue to face stigma and discrimination based on their actual or perceived health status, socioeconomic status, age, sex, sexual orientation, gender identity or other grounds. The ZDHS of 2018 reports discriminatory attitudes towards people living with HIV. Women and men were asked two questions to assess discriminatory attitudes towards people living with HIV. Participants with discriminatory attitudes towards people living with HIV are those who say that they would not buy fresh vegetables from a shopkeeper or vendor if they knew that person had HIV or who say that children living with HIV should not be allowed to attend school with children who do not have HIV. Based on these questions, the ZDHS shows that about 27 per cent of women and 23 per cent of men demonstrated discriminatory attitudes towards PLHIV. The findings suggest differences in attitudes towards PLHIV between men and women in rural and urban areas. About 20 per cent of women and 17 per cent of men in urban areas have discriminatory attitudes, compared to 33 per cent of women and 28 per cent of men in rural areas. Discriminatory attitudes are highest in Luapula (47 per cent for women and 39 per cent for men) and lowest in Copperbelt for women (17%) and Lusaka for men (16%). Discriminatory attitudes towards PLHIV decrease with increasing education among both women and men. 45 per cent of women and 41 per cent of men with no education have discriminatory attitudes, compared to seven per cent of women and six per cent of men with a higher education (ZDHS, 2018).

## **1.2 The PLHIV Stigma Index**

The People Living with HIV Stigma Index is a tool to be used by and for people living with HIV, including key populations to assess the extent to which they experience stigma and discrimination. The Stigma Index tool is based on the GIPA (Greater Involvement of People living with HIV and AIDS) principle. The research is driven by PLHIV and their networks. This provides them with evidence and opportunity to address challenges in their communities and catalyse change as well as empowerment with research and analytical skills.

The People Living with HIV Stigma (Stigma Index) was first launched in 2008. The tool was developed by the Global Network of People Living with HIV (GNP+); the International Community of Women Living with HIV (ICW); the International Planned Parenthood Federation

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<sup>7</sup> Pescosolido BA, Martin JK. The Stigma Complex. *Annu Rev Sociol.* 2015 Aug; 41:87-116. doi: 10.1146/annurev-soc-071312-145702. Epub 2015 May 4. PMID: 26855471; PMCID: PMC4737963.

<sup>8</sup> Discrimination. *Stanford Encyclopaedia of Philosophy.*

<sup>9</sup> National Aids Strategic Framework (NASF) 2017 - 2021

<sup>10</sup> HIMS. 2020

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(IPPF); and the Joint United Nations Programme on HIV/AIDS (UNAIDS). The Stigma Index has always been a project led by and for PLHIV.

In 2018, the Stigma Index tool was updated to Stigma Index 2.0 to reflect the shift in the HIV epidemic and the global response. Amongst the changes is the focus on specific populations to better understand how different groups of people living with HIV are affected by stigma and discrimination. These include key populations as well as an expanded healthcare section to look at the impact of stigma on health and access to health across the whole continuum of care, not just HIV services. Stigma Index 2.0 is the version that was used in this study.

The PLHIV Stigma Index 2.0 utilises a standardised methodology to study and capture data on PLHIV experiences of stigma and discrimination. The findings are instrumental in increasing collective understanding of stigma and discrimination and detecting changes and trends over time. The introduction of the standardised methodology is key to increase comparability between the different Stigma Index implementations over time and across different settings. The evidence gathered by the tool helps to shape future programmatic interventions by revealing areas of need and gaps in existing programming. The People Living with HIV Stigma Index is a powerful advocacy tool to influence policy and support the collective goal of governments, NGOs and activists to reduce stigma and discrimination related to HIV.

### **1.3 Rationale and objective**

The 2012 Stigma Index covered two districts: Mkushi and Lusaka. The sample size was 865 consisting of 605 general PLHIV and 260 KPs. However, the study was not nationally representative. While 30 per cent of the participants identified with ever having belonged to a key population, the number of participants belonging to any one KP group was small, affecting the extent to which the results could inform reflections on the experiences of other people living with HIV belonging to each of the key populations. Among other things, the study recommended that NZP+ and its partners must advocate for a legislative framework that embraces the heterogeneity of PLHIV to address the causes of stigma as well as build capacity among local organisations to provide support services including counselling to people living with HIV and key populations. It was also recommended that people living with HIV must be engaged in a participative manner in the design and implementation of programmes that target them. Methodologically, a study that also utilises a qualitative methodology to capture the depth and nuance of stigma experienced was recommended.

In addition, this 2012 Zambia Stigma Index study was conducted over a decade ago, the context of HIV epidemiological situation and stigma in Zambia has evolved overtime since the last 2012 study. Consequently, it was important that NZP+ and partners conducted another Stigma Index study to understand the status of stigma and discrimination in the country and adequately capture the experiences of people living with HIV and key populations living with HIV, as well as to respond to changes in global treatment guidelines and to better understand the persistent barriers to HIV testing, prevention and treatment. Stigma remains one of the biggest barriers to accessing health care services for people living with HIV. Therefore, addressing it among people living with HIV and key populations remains an urgent priority. Stigma has a negative impact on the health of PLHIV and contributes to physical and psychological stress, lack of confidence, violence, job loss, and social exclusion. Even more, gay men and other men who have sex with other men (MSM), transgender people, sex workers and people who use injecting drugs – often referred to as key populations – are situated at the intersection of HIV-related stigma and prejudice against their identities, occupations or behaviours, often exacerbating their experiences of stigma and discrimination. It is important, therefore, to understand their experiences of stigma, as well as to explore the intersectionality between HIV and lived experiences.

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NZP+ is a national organisation for People Living with HIV (PLHIV) in Zambia, which was established in 1996 to help improve the quality of life of PLHIV through support, communication, and representation of its members. NZP+, envisions to empower members into leading healthy, productive and sustainable lives. The organisation has evolved from a group of 28 members in 1996 into a national network of PLHIV support groups with approximately 200,000 PLHIV. The organisation has built capacity in its members for community mobilisation to increase demand, uptake and access to HIV prevention, treatment, care and support services. NZP+ employs a human rights-based approach in all its programming, through establishing and strengthening community-based and local structures to demand improved policies and programmes that promote inclusiveness and accessibility to health services.

NZP+ has vast experience in conducting research including, but not limited to, access to health services by PLHIV, PLHIV Stigma Index, Criminalisation Scan, Human Rights Count and Assessment of SRHR of young people living with HIV. The network has also helped to strengthen the voices of people living with HIV by working to ensure that their interests are represented at various levels of governance.

The overall objective of the Stigma Index 2.0 is to generate evidence on stigma and discrimination experienced by PLHIV including KPs in Zambia to influence policy action.

Specific objectives of the PLHIV Stigma Index 2.0 in Zambia are:

- To estimate the level of stigma and discrimination among PLHIV including key populations (KPs) in Zambia;
- To understand the experiences of stigma and discrimination among PLHIV including key population groups in Zambia;
- To inform and increase advocacy on the protection and promotion of the human rights of PLHIV including KPs through engagement of national institutions and stakeholders; and
- To build and develop the capacities and skills of PLHIV including KPs through their involvement as co-researchers for the Stigma Index 2.0 study.

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## 2.0 METHODOLOGY

The PLHIV Stigma Index 2.0 study utilises a standard methodology with a standardised study instrument/questionnaire. Based on the recommendations of the 2012 Stigma Index and the guidance from the International Partnership on the Stigma Index 2.0, this study utilised a concurrent mixed methods design involving the cited standardised study methodology and an explorative case study qualitative methodology to provide narrative evidence to the nuanced nature of lived experiences of stigma related to living with HIV.

### 2.1 Geographical scope of the study

The Stigma Index 2.0 is a study designed to reflect a national profile. Consequently, the geographical scope of this research was set to cover all the 10 provinces of Zambia. On these grounds, 25 out of 116 districts were selected for incorporation into the sample using the following criteria:

- HIV prevalence, urban and rural districts, and chance of recruiting key populations other than sex workers;
- The other factor considered in selecting sample districts is the assumption that the rate of HIV prevalence influences societal attitudes in the sense that people may be more accepting if the HIV phenomenon is widespread than when it is hidden or not widespread; and
- To enable a comparative analysis of stigma across differing rates of HIV prevalence, areas of both low and high prevalence rates were selected into the sample. Low prevalence areas are defined as those with rates below five per cent while high prevalence areas are defined as those areas with rates six per cent and above.

The implementation guidelines from the GNP+ require that the total sampled districts must cover at least 50 per cent of the total PLHIV. However, sampling purely on this criterion would mean that only areas with large PLHIV populations make it into the sample. This would bias against small PLHIV population districts where stigma may be heightened because the HIV prevalence is lower and uncommon.

Hence, further considerations such as whether the district is rural or urban were considered as they have the potential to influence attitudes towards PLHIV, i.e., urban metropolitan areas may be more accepting of diverse sexual behaviours than rural and culturally conservative areas. Thus, the selected districts include rural districts and urban districts in each province. Further consideration was given to include transit areas which tend to be key population and HIV hotspots. In Lusaka province, Kafue and Chirundu towns were included into the sample alongside Lusaka district which houses Lusaka city.

Using the above criteria, 24 districts were selected into the sample. To enable a comparison with Stigma Index data from 2012, Mkushi, which did not meet the inclusion criteria stated here was also included into the sample making the total number of 25 districts. Finally, the sample allocation for each district was disaggregated by sex. The total 25 sampled districts account for 52 per cent of the national PLHIV population. However, since Zambia currently does not have estimates at district level by sex, the national proportional estimate of women (62%) vs men (38%) was used to determine the proportional samples in each district as shown below.

**Table 2: Selected sample by province and district**

| Province                | District      | Status | District Prevalence | No. of PLHIV | Number of residents on ART above 15 | Provincial Prevalence |
|-------------------------|---------------|--------|---------------------|--------------|-------------------------------------|-----------------------|
| <b>Lusaka Province</b>  | Lusaka        | Urban  | 15.0%               | 310,200      | 260600                              | 15.1%                 |
|                         | Kafue         | Urban  | 12.5%               | 17,300       | 15100                               |                       |
|                         | Chirundu      | Rural  | 7.5%                | 3,700        | 3100                                |                       |
| <b>Copperbelt</b>       | Kitwe         | Urban  | 13.4%               | 73,300       | 63,500                              | 15.4%                 |
|                         | Mpongwe       | Rural  | 17.0%               | 15,000       | 11900                               |                       |
|                         | Chingola      | Urban  | 13.8%               | 31,500       | 24,500                              |                       |
| <b>Southern</b>         | Livingstone   | Urban  | 16.0%               | 26,500       | 19700                               | 12.4%                 |
|                         | Sinazongwe    | Rural  | 5.4%                | 5,600        | 4700                                |                       |
|                         | Mazabuka      | Urban  | 13.5%               | 24,800       | 19,700                              |                       |
| <b>Eastern Province</b> | Chipata       | Urban  | 15.0%               | 33,300       | 29500                               | 7.4%                  |
|                         | Katete        | Rural  | 9.0%                | 13,700       | 11,500                              |                       |
| <b>Central Province</b> | Kabwe         | Urban  | 16.0%               | 34,500       | 30600                               | 12.4%                 |
|                         | Mumbwa        | Rural  | 11.2%               | 17,400       | 14100                               |                       |
|                         | Mkushi        | Rural  | 12.0%               | 14,200       | 11,500                              |                       |
|                         | Kapiri Mposhi | Urban  | 13.6%               | 29,600       | 25,500                              |                       |
| <b>Western Province</b> | Mongu         | Urban  | 20.0%               | 22,600       | 19700                               | 10.0%                 |
|                         | Sesheke       | Rural  | 17.8%               | 13,200       | 9,300                               |                       |
| <b>Northern</b>         | Kasama        | Urban  | 9.0%                | 20,400       | 15800                               | 5.6%                  |
|                         | Mpulungu      | Rural  | 6.5%                | 6,000        | 3800                                |                       |
| <b>Luapula</b>          | Mansa         | Urban  | 9.5%                | 17,500       | 13700                               | 7.9%                  |
|                         | Nchelenge     | Rural  | 9.5%                | 13,200       | 9,300                               |                       |
| <b>Muchinga</b>         | Mpika         | Urban  | 8.4%                | 9,700        | 8100                                | 5.4%                  |
|                         | Nakonde       | Rural  | 6.0%                | 8,400        | 5400                                |                       |
| <b>North Western</b>    | Solwezi       | Urban  | 9.5%                | 11,400       | 9100                                | 6.1%                  |
|                         | Mwinilunga    | Rural  | 3.5%                | 3,200        | 2000                                |                       |

Source: Spectrum 2021

## 2.2 Study participants

As specified in the Stigma Index 2.0 protocol guidelines, only people living with HIV were study participants. The sample size for the Stigma Index 2.0 was calculated using the Stigma Index calculator. This calculator is premised on the precision around the estimated prevalence of avoidance of seeking healthcare by PLHIV because of fear of stigma due HIV status. In Zambia, the estimated prevalence of avoidance of seeking healthcare due to anticipated stigma by PLHIV as of the previous 2012 Stigma Index was 13 per cent. With a precision between three per cent and five per cent (following the rule of thumb provided by the calculator), the sample size is calculated to be between 696 and 1, 931. The sample size for this study was determined to be the upper limit of this range, hence using a target precision of three per cent, resulting in a target sample size of 1, 931.

The sample included appropriate numbers of the various PLHIV population subgroups such as women, young people, PLHIV who are not currently linked to care and/or treatment and key populations (i.e., gay men and other men who have sex with men, sex workers, transgender people, and people who use drugs).

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The study was designed to include people who are aware that they have been living with HIV for at least 12 months with various characteristics as reflected below:

- Confirmed resident in the district for at least 3 months;
- Aged 18 and above;
- Able to speak any of the 7 official local languages of the interview (Bemba, Lozi, Kaonde, Lunda, Luvale, Tonga, Nyanja);
- Able and willing to provide informed consent to an interview;
- Aware that they are living with HIV for at least 12 months; and
- Able to provide informed consent in terms of understanding all elements of the study.

In addition, people were excluded if they:

- Were under 18 years old;
- Had known their HIV status for less than one year;
- Had already participated in the current study; and
- Were not living with HIV, even if they were from a key population.

### **2.3 Sample distribution**

Given the methodological requirement that at least 25 per cent of the sample has to be reserved for key populations, 482 spaces were allocated to participants from KP groups. In the context of this study, key populations included people who use drugs, sex workers, transgender people and gay men and other men who have sex with men. Allocation of KP samples per district was made in consideration of those districts generally considered to be KP hotspots in view of GNP+ guidance that each KP group must have a representation of at least 50 people. Given the lack of sex disaggregated estimates at district level, district samples were disaggregated into women and men proportionally to reflect the national profile, which show that 62 per cent of women and 38 per cent of men are living with HIV as indicated below. In addition, according to the UNAIDS country factsheet, 90 per cent of PLHIV are on ART, while 10 per cent are not. Of the overall sample, thus, 10 per cent were reserved for people not on care, translating to 193 participants.

**Table 3: Sample allocation for KPs by district and sex**

| <b>Sample Allocation for PLHIV (not part of KP group), by district and sex, n=1,449</b> |                       |                         |                    |            |              |                                  |
|-----------------------------------------------------------------------------------------|-----------------------|-------------------------|--------------------|------------|--------------|----------------------------------|
| <b>District</b>                                                                         | <b>HIV Prevalence</b> | <b>PLHIV Population</b> | <b>Sample Size</b> | <b>Men</b> | <b>Women</b> | <b>Participants not in care*</b> |
| Chingola                                                                                | 15.6                  | 29, 100                 | 59                 | 22         | 37           | 8                                |
| Chipata                                                                                 | 15.7                  | 31, 500                 | 63                 | 24         | 39           | 8                                |
| Chirundu                                                                                | 23.5                  | 7, 200                  | 14                 | 5          | 9            | 2                                |
| Kabwe                                                                                   | 17.8                  | 33, 600                 | 68                 | 26         | 42           | 9                                |
| Kafue                                                                                   | 13.1                  | 15, 000                 | 30                 | 11         | 19           | 4                                |
| Kapiri Mposhi                                                                           | 14                    | 24, 000                 | 49                 | 19         | 30           | 6                                |
| Kasama                                                                                  | 9.1                   | 18, 200                 | 37                 | 14         | 23           | 5                                |
| Katete                                                                                  | 9.9                   | 13, 000                 | 26                 | 10         | 16           | 3                                |
| Kitwe                                                                                   | 14.2                  | 71, 800                 | 144                | 55         | 89           | 19                               |
| Livingstone                                                                             | 23.7                  | 25, 000                 | 50                 | 19         | 31           | 7                                |
| Lusaka                                                                                  | 15.5                  | 263, 300                | 529                | 201        | 328          | 71                               |
| Mansa                                                                                   | 11.5                  | 18, 200                 | 37                 | 14         | 23           | 5                                |
| Mazabuka                                                                                | 16.3                  | 24, 000                 | 48                 | 18         | 30           | 6                                |
| Mkushi                                                                                  | 12.2                  | 11, 700                 | 24                 | 9          | 15           | 3                                |
| Mongu                                                                                   | 20.4                  | 23, 800                 | 48                 | 18         | 30           | 6                                |
| Mpika                                                                                   | 12                    | 8, 600                  | 17                 | 6          | 11           | 2                                |
| Mpongwe                                                                                 | 22.6                  | 18, 000                 | 36                 | 14         | 22           | 5                                |
| Mpulungu                                                                                | 10.5                  | 8, 200                  | 16                 | 6          | 10           | 3                                |
| Mumbwa                                                                                  | 14.2                  | 20, 500                 | 41                 | 16         | 25           | 5                                |
| Mwinilunga                                                                              | 5                     | 2, 900                  | 6                  | 2          | 4            | 2                                |
| Nakonde                                                                                 | 9.9                   | 8, 300                  | 17                 | 6          | 11           | 2                                |
| Nchelenge                                                                               | 12                    | 14, 200                 | 29                 | 11         | 18           | 4                                |
| Sesheke                                                                                 | 20.6                  | 8, 000                  | 16                 | 6          | 10           | 2                                |
| Sinazongwe                                                                              | 8.6                   | 7, 300                  | 15                 | 6          | 9            | 2                                |
| Solwezi                                                                                 | 12.5                  | 14, 400                 | 30                 | 11         | 19           | 4                                |
| <b>Total</b>                                                                            |                       | <b>719, 800</b>         | <b>1, 449</b>      | <b>549</b> | <b>900</b>   | <b>193</b>                       |

\* “Participants not in care” is presented as a standalone category. However, they are incorporated into the sample size distributed by sex, as they are also men and women (1, 449 = 549 males + 900 females)

**Table 4: Sample allocation by district and key population participants**

| District    | MSM | SW  |           | Transgender | PWUD |
|-------------|-----|-----|-----------|-------------|------|
|             |     |     | Men/Women |             |      |
| District    |     |     |           |             |      |
| Chingola    | 7   | 15  | 6M/9W     | 4           | 2    |
| Chipata     | 8   | 20  | 8M/12W    | 4           | 1    |
| Chirundu    | 7   | 15  | 6M/9W     | 2           | 1    |
| Kabwe       | 10  | 15  | 6M/9W     | 2           | 1    |
| Kafue       | 10  | 15  | 4M/6W     | 2           | 5    |
| Kapiri      | 7   | 20  | 8M/12W    | 2           | 1    |
| Kitwe       | 27  | 15  | 6M/9W     | 11          | 15   |
| Livingstone | 10  | 13  | 5M/7W     | 5           | 1    |
| Lusaka      | 38  | 60  | 23M/37W   | 12          | 20   |
| Mazabuka    | 6   | 15  | 6M/9W     | 2           | 1    |
| Mongu       | 7   | 15  | 6M/9W     | 2           | 1    |
| Solwezi     | 7   | 20  | 8M/12W    | 2           | 1    |
| Total       | 144 | 238 |           | 50          | 50   |
| Total       | 482 |     |           |             |      |

## 2.4 Sampling and Recruitment

Systematic sampling was used to select participants for the study. Primarily, the sampling frame for the Stigma Index was the list of PLHIV registered within the district with PLHIV organisations, such as NZP+ and related organisations; and clients receiving ART from a designated ART site or clinic in the sampled district. 75 per cent of the participants (covering the sample allocation above) were recruited using venue-based systematic sampling.

The process involved selecting every second person attending a support group; community ART access point; KP safe spaces or hubs and homes; or at an ART site. Various organisations namely community-based organisations; Key Population Consortium; FHI 360 community resource partners; Zambia Network of Young people living with HIV; Treatment Advocacy and Literacy Campaign; and NZP+ network partners, who worked with PLHIV and key populations in the various districts, were approached to link the study interviewers to participants in the initial phase. Additionally, although currently there was no network partner that was specifically a women's organisation, attempts were made to reach out to community level organisations whose work focused on women, such as the Non-Governmental Coordinating Council. The distribution of these network partners enabled the study to counter any spatial biases. The selection was done in collaboration with community liaisons, who were persons with networking relationships with NZP+.

To ensure that people who were not in care or not registered with a network organisation and especially members of the key populations were recruited into the study as well, the limited chain referral sampling method was also utilised. To do this, each participant who completed the study was provided with four study coupons to share with peers who were also living with HIV whom they thought would be interested in participating in the study. Each research participant was given a series of codes for the number of participants they were to recruit, upon which they would be checked for eligibility and interviewed by a research assistant. These systems enabled the research team to monitor recruitment and ensure that quotas were met as close as possible.

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For the qualitative interviews, purposive sampling was used to select participants from within the quantitative sample. The qualitative component of the Stigma Index provided in-depth information from selected participants to provide nuance, context and in-depth understanding of the various forms of stigma and discrimination, which participants experienced. In total, 60 people were selected for qualitative interviews. In-depth interviews were selected because they offered the opportunity of privacy and confidentiality – which is essential given the criminalisation of KPs in Zambia and that during the time of the research there was a strong anti-KP national discussion.

The criteria for qualitative method sampling considered recruiting a man and a woman as well as one member of each key population (where they were available) per district. However, because it was difficult to find participants willing to have a second interview, the sampling quota for the qualitative interviews were filled on a rolling basis, and aimed to include PLHIV in all their diversity, including young PLHIV (those aged between 18-24 years), key populations living with HIV and women living with HIV. Upon completing consent procedures, those who consented to participate in the research proceeded to be interviewed using the prepared interview guide. For those who consented, the interview was recorded while notes were taken of those who did not consent to being recorded. The interview was structured to be conversational.

## **2.5 Data collection**

There were 67 research assistants for this study who were selected by NZP+ and their consortium partners. All the research assistants were individuals living with HIV. The team was composed of 55 per cent male and 45 per cent female, 74 per cent non-KP and 26 per cent KP, including FSW, MSM and TG representatives. To prepare them for their roles, a comprehensive five-day training programme was conducted at the Mika Convention Centre in December of 2022.

The training programme covered various essential aspects of the Stigma Index 2.0, including participant recruitment, consent procedures, interviewing techniques and processes, managing challenging situations with the participants and providing referrals for services and information. Additionally, the training included a pilot phase for the research tool, allowing for feedback and review to ensure its relevance and applicability. This pilot phase was crucial in testing both the participants' and the research assistants' understanding of the tool and its practical implementation.

Study data were collected using the standardised Stigma Index 2.0 questionnaire provided by the International Partnership, using KOBO collect, a digital platform. The questionnaire was administered by the research assistants using android tablets – each research assistant had their own tablet. The study questionnaire was translated into the 7 languages at the Department of Literature and Languages at the University of Zambia by professional translators.

In-depth interviews were also collected on the same tablets by a selected team of research assistants. The interview followed a guide developed to complement the quantitative study tool. It was designed to predominantly solicit experiences pertaining to the lived experiences of PLHIV and KPs regarding stigma and discrimination. The interviews were recorded and translated to summary notes due to time constraints.

## **2.6 Data management and analysis**

This study was designed to be a mixed methods concurrent design with both the quantitative and qualitative elements occurring at the same time.

A team of 6 data associates were retained by the NZP+ to support the process of data management. Among other things, they were responsible for ensuring that data collection followed the laid down procedures, providing real time support to the data collection process by checking the data for completeness, consistency and errors. The completed data sets were stored on a secured drive.

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For the quantitative data analysis, the anonymised quantitative data collected from the study were checked for consistency and errors and downloaded into a csv file. This data was pre-coded with numerical values. Descriptive and regression analysis using STATA 22 were performed on the data to provide a detailed understanding pertaining to the stigma situation, including how gender and spatial characteristics interact to produce experiences for people living with HIV and key populations. The clean dataset from the study was shared with GNP+ to be stored securely as part of the global PLHIV Stigma Index database.

For the qualitative data analysis, interview data were transcribed and coded using sensitising concepts and analysed in NVivo 12. Thematic analysis in line with the study objectives was utilised to interpret qualitative data from participants using repeating ideas. This process of data analysis complemented the analysis of the quantitative data to provide in-depth and nuanced narrative evidence of experiences.

### 3.0 RESULTS

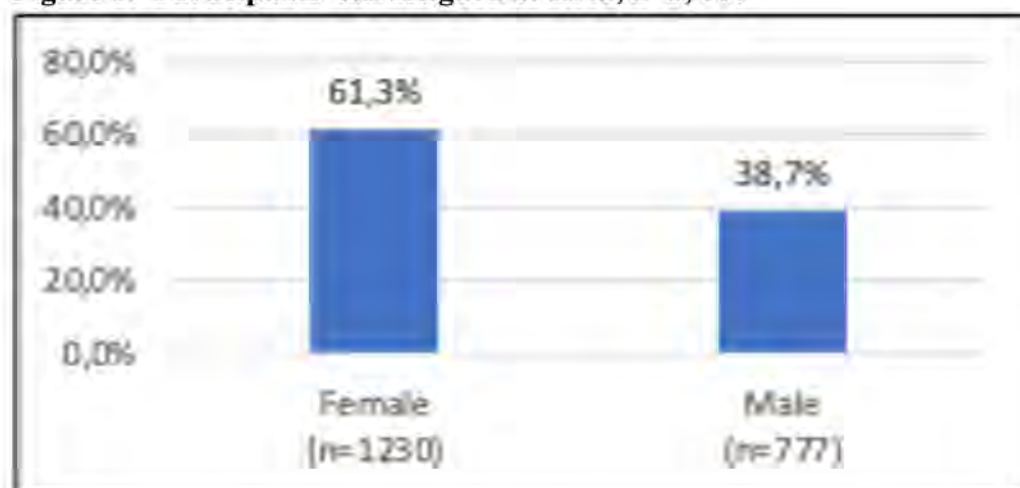
This section presents the findings of the study of the Stigma Index 2.0. Given that the study was guided by four objectives, which led to sometimes intersecting findings, results of the analysis are presented thematically following the key sections of the Stigma Index tool (i.e., participant sociodemographic information, experience of disclosure, levels and experience of external stigma, levels and experience of internal stigma and discrimination and experience of access to services, information and rights).

#### 3.1 Sociodemographic characteristics of the participants

This section presents the sociodemographic characteristics of participants. It sheds light on the multifaceted aspects of their lives, considering various demographic variables i.e., age, gender, education and employment status.

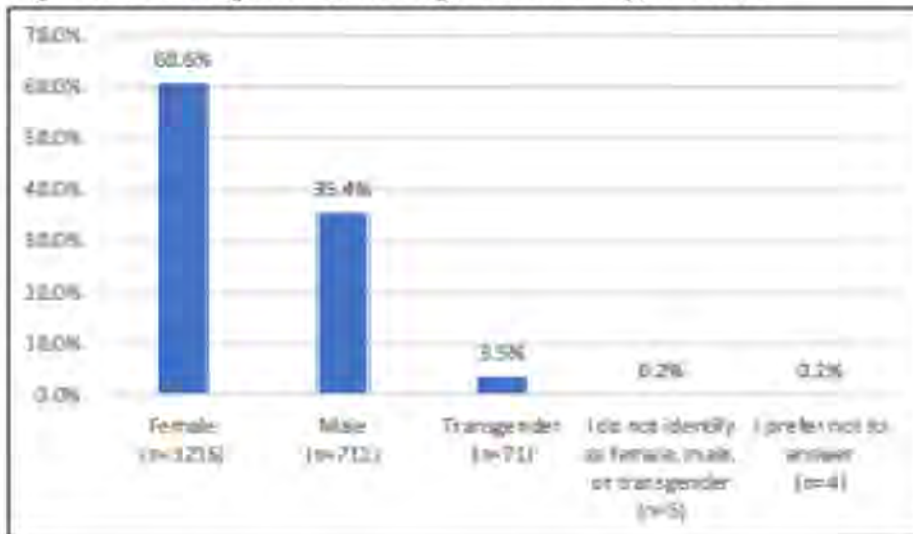
The study had planned to sample 1, 931 participants. However, due to the methods of recruitment used and willingness of people to participate, the study reached 76 more participants taking the total number of participants to 2, 007. Regarding the distribution of participants based on their assigned sex at birth, the findings, as shown in **figure 1** below, indicate that out of the sample size of 2, 007 participants, 61.3 per cent of the participants (n=1, 230) were assigned female at birth, while 38.7 per cent (n=777) participants were assigned male at birth. The sampling methodology employed in this study was carefully designed to ensure a representative allocation of participants from women and men, considering the respective proportions of women and men within the total population of individuals living with HIV in Zambia. Specifically, the allocation was set at 62 per cent for women and 38 per cent for men, mirroring the distribution observed in national HIV statistics. The distribution presented above indicates close alignment with the planned sampling indicating that the research adhered to its proposed sample allocations.

**Figure 1: Participants' sex assigned at birth, n=2, 007**



When participants were asked about their current gender identity, 60.6 per cent identified as female, 35.4 per cent as male, 3.5 per cent as transgender, 0.2 per cent did not identify as female, male or transgender and 0.2 per cent preferred not to answer the question (Figure 2).

**Figure 2: Participants' current gender identity, n= 2007**



Of these participants, 45.5 per cent were aged 40 years and above (n=913). The age group 35 to 39 years had 246 participants accounting for 12.3 per cent of all participants in the sample while participants aged 30 to 34 years accounted for 12 per cent of the sample (n=241). There were 301 participants in the age group 25 to 29 years accounting for 15 per cent of the sample while 11.5 per cent of the participants were aged between 20 to 24 years (n=231). The age group 18 to 19 years only had 75 participants, accounting for 3.7 per cent of the sample (Figure 3). The summary statistics for the age distribution show that the modal age of the sample was 23 years, meaning that most of the participants were aged 23 years, ranging from 18 to 73. The median age was 38 years, implying that half of the participants were aged 38 years and above.

**Figure 3. Participants' age, n=2, 007**

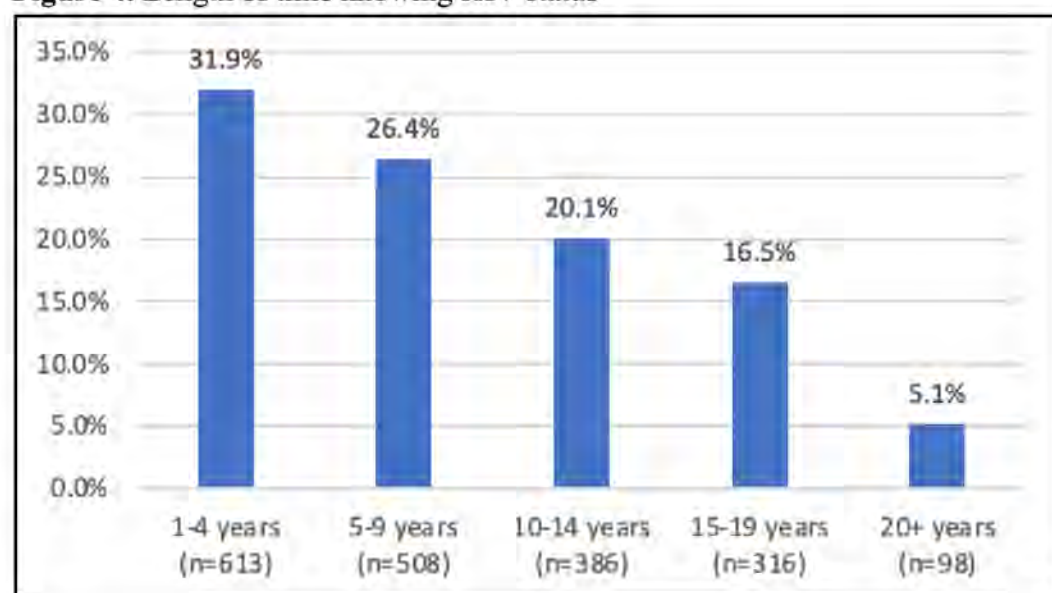


The study also considered household size by looking at the number of children. About a quarter of the participants did not have any children in their household that they were taking care of (23.6%, n=473). 15.8 per cent (n=315) had one child in their household, 18.6 per cent had two children in their household and 16.0 per cent (n=319) had three children in their household. It can also be seen that as the number of children per household increases beyond three, the frequency gradually declines. For instance, households with four children account for 11.5 per cent of the sample while those with five children represent only 6.2 per cent of the sample and so on. The largest household had 15 children signifying the existence of larger family units within the sample.

Of all participants, 31.4 per cent identified as part of a key population group, with 6.5 per cent (n=131) of gay men and other MSM; 25.0 per cent (n=502) of sex workers; 6.6 per cent (n=113) of transgender people; and 5.3 per cent (n=106) of people who use drugs. It is important to recognise that one participant may belong to several key population groups. While not a key population in the context of this study, it should be noted that 12.1 per cent of the participants were living with a disability (n=242). Even though the limited sample sizes per key population limit the generalisability of the findings of this study, the findings demonstrate the diversity of experiences and identities represented in the study sample.

Inclusion into the study required that participants were aware of their HIV status for a minimum of one year. The findings show that 31.9 per cent (n=613) of participants had been aware of their HIV status between one and four years, while 26.4 per cent (n=508) had been aware of their status for between five to nine years. Those who had known their status for a period between 10 to 14 years were 20.1 per cent (n=386) of the sample, while 16.5 per cent (n=316) had knowledge of their status for 15 to 19 years. A smaller proportion of the participants (5.1%, n=98) had been aware of their HIV status for 20 years or more. These findings indicate that the average duration of knowledge of status was 8.9 years, with the longest being 38 years, demonstrating that a significant majority of the participants had been aware of their HIV status for more than four years and provides insights into the potential experiences of stigma among participants and their subsequent coping mechanisms.

**Figure 4.** Length of time knowing HIV status



Participants were also asked whether they were currently in an intimate/sexual relationship. The results revealed that 67.9 per cent of the participants (n=1,363) were in an intimate relationship while 32.1 per cent were not. Among those who were in an intimate relationship, 60.1 per cent (n=818) reported that their partner(s) was living with HIV, while 16.2 per cent (n=322) reported that their partner was HIV negative. Participants who were unsure of their partners' status made up 16.2 per cent of the sample (n=221).

Most of the participants in this study, accounting for 61.8 per cent of the sample (n=1,238), were not part of a network or support group for PLHIV. Among the key population groups, more PWUD (54.7%) and TG people (53.1%) were part of a support group than other key populations (47.3 per cent for MSM and 38.9 per cent for sex workers) or non-KP participants (37.3%).

**Figure 5.** PLHIV network or support group membership by key population



The findings show that 14.9 per cent of the sample were currently pursuing any type of formal education. When looking at the highest level of completed education (Figure 6), most participants (47.3%) had completed their secondary school education. This was followed by primary education at 30.1 per cent, no formal education at 7.5 per cent, while education up to vocational level was 4.9 per cent and tertiary education was 10.1 per cent.

**Figure 6.** Highest level of completed education, n=2,007

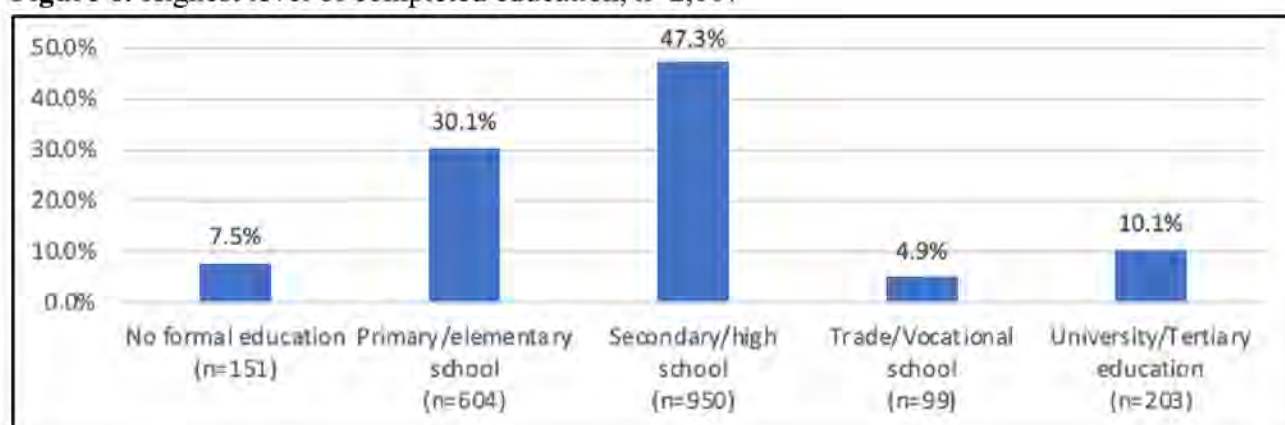
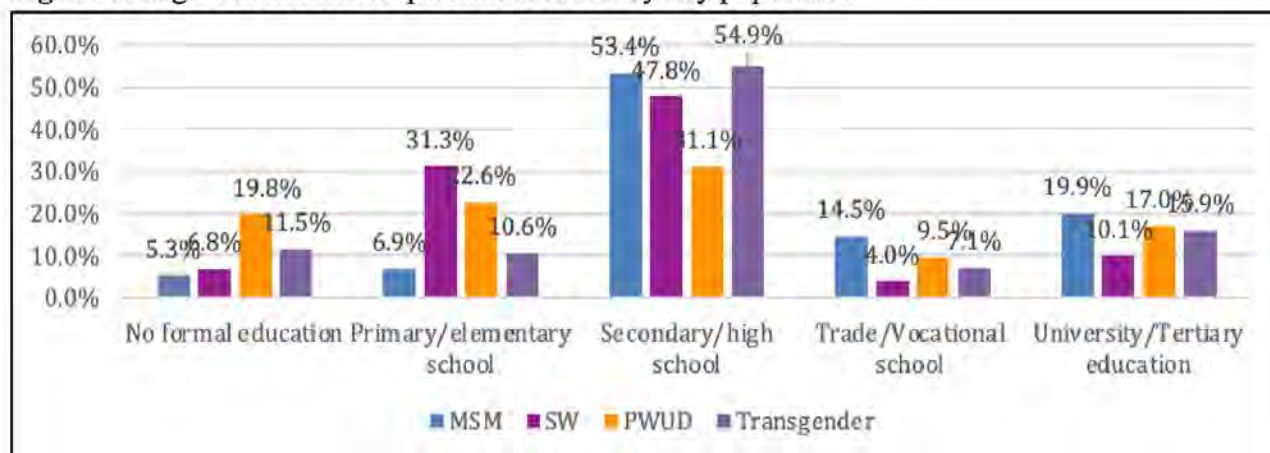


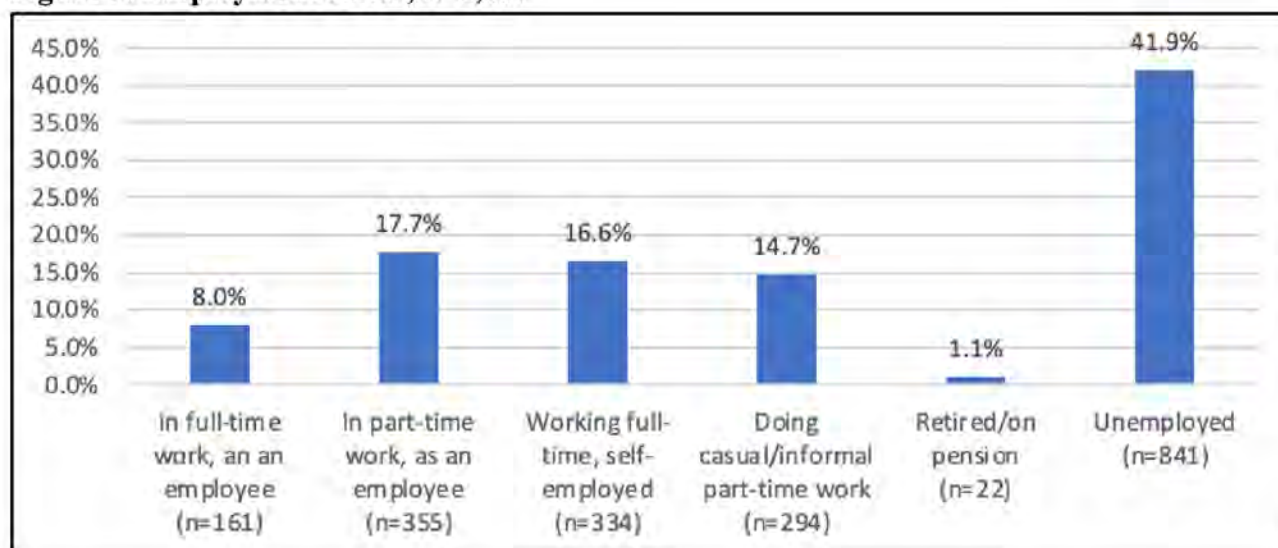
Figure 7 shows the highest level of completed education of key population participants. The findings reveal that a significant proportion of KP attained secondary level with the highest being Transgender at 54.9 per cent. Those with no formal education was highest among PWUD at 19.8 per cent. Those that attained tertiary /university education was highest among MSM at 19.9 per cent and least among sex workers at 10.1 per cent, while sex workers had the highest proportion of those that attained primary education level at 31.3 per cent.

**Figure 7. Highest level of completed education by key population**



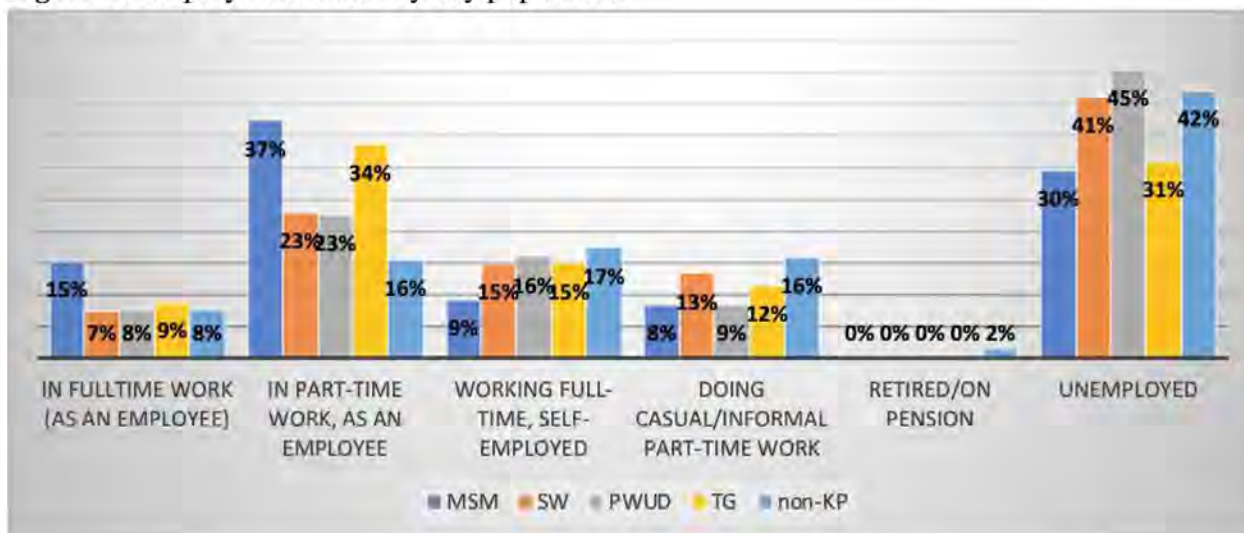
Analysis of the employment status of the participants reveals that a substantial portion of the sample (41.9%, n=841) was unemployed. Taking a closer look at those who were unemployed reveals that 46.3 per cent of women were unemployed, compared to 35.0 per cent of men. In addition, 17.7 per cent of the participants (n=355) engaged in part-time work, while 14.7 per cent participants (n=294) were involved in casual part-time employment, 16.6 per cent of the sample (n=334 individuals) were employed full-time but not as formal employees, whereas only 8.0 per cent of participants (n=161) were full-time employees. A small proportion of the sample, 1.1 per cent of participants (n=22) were retired or on pension.

**Figure 8: Employment status, n=2,007**



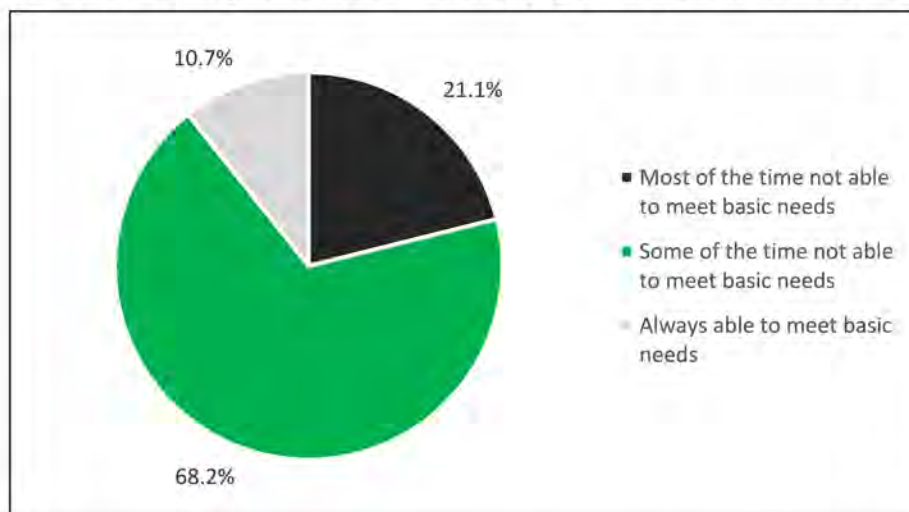
When looking at unemployment by key population (Figure 9), unemployment rates were highest for PWUD (45.3%), followed by non-KP (42.1%) and SW (41.2%).

**Figure 9: Employment status by key population**



The findings in Figure 10 show that a significant proportion of participants (representing 68.2 per cent of the sample some of the time and 21.2 per cent of participants most of the time) were unable to meet their basic needs. Only 10.7 per cent of participants indicated always being able to meet their basic needs. These findings highlight the considerable difficulty experienced by the participants in meeting their basic needs and resonate with national statistics, which indicate that over half (54%) of the Zambian population live in poverty, defined terms of material deprivation as an inability to afford minimum basic human needs comprising food and non-food items within one's total income.<sup>10</sup>

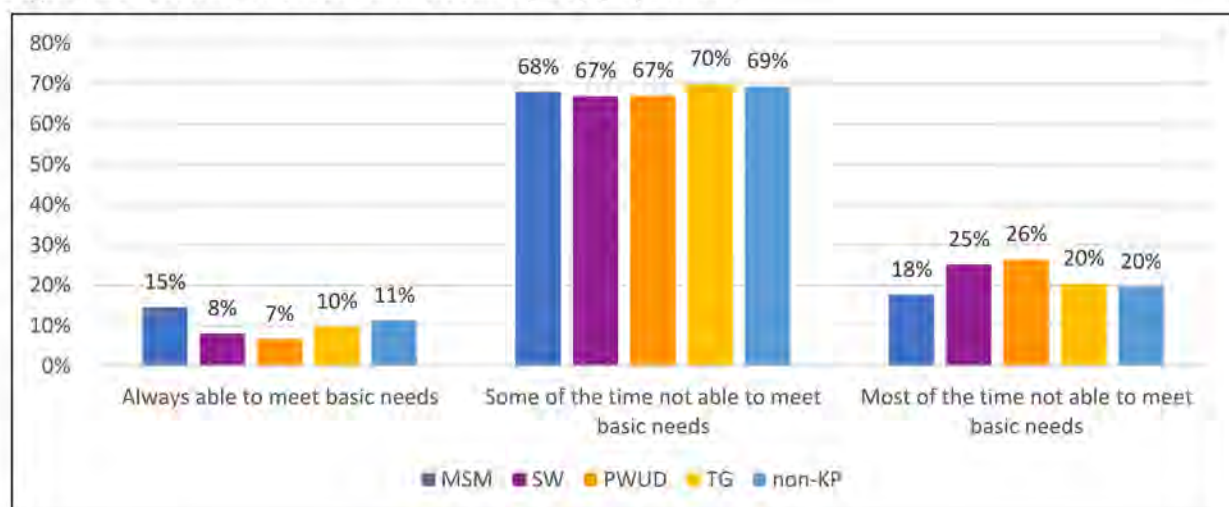
**Figure 10: Ability to meet basic needs (e.g., food, shelter or clothing)**



Analysis of the ability to meet basic needs among key populations showed that sex workers (25.1%) and people who use drugs (26.4%) were unable to meet their basic needs most often (Figure 11).

<sup>10</sup> Zambia Statistics Agency (ZAMSTATS). 2015. Living Conditions Monitoring Survey Report. Lusaka

**Figure 11: Ability to meet basic needs by key population**

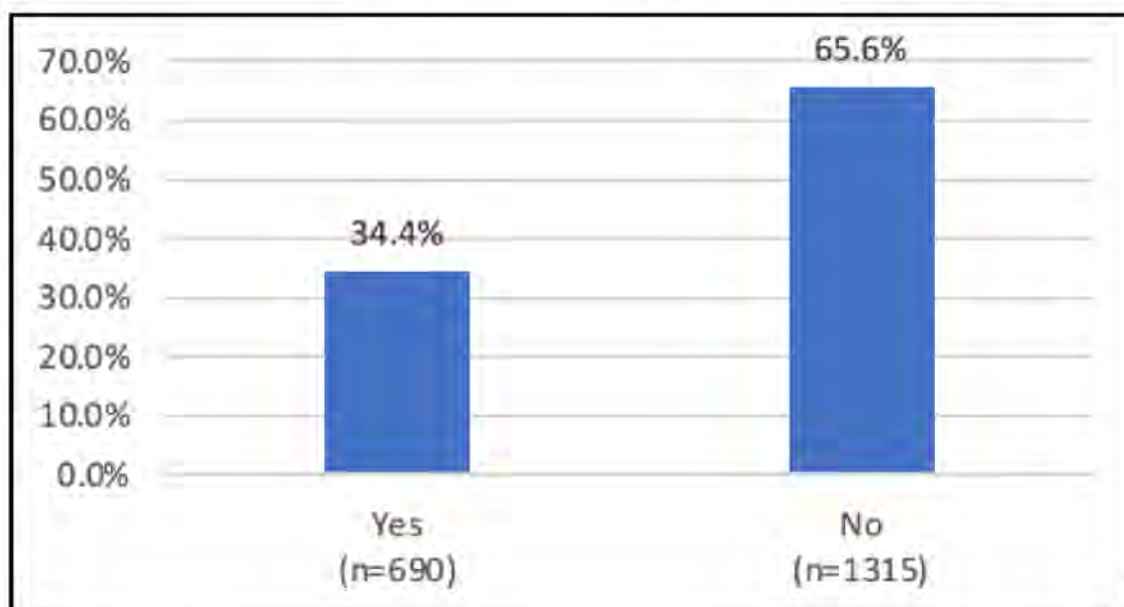


### 3.2 HIV Disclosure

This section provides findings on the dynamics of status disclosure by participants and how that affected their lives.

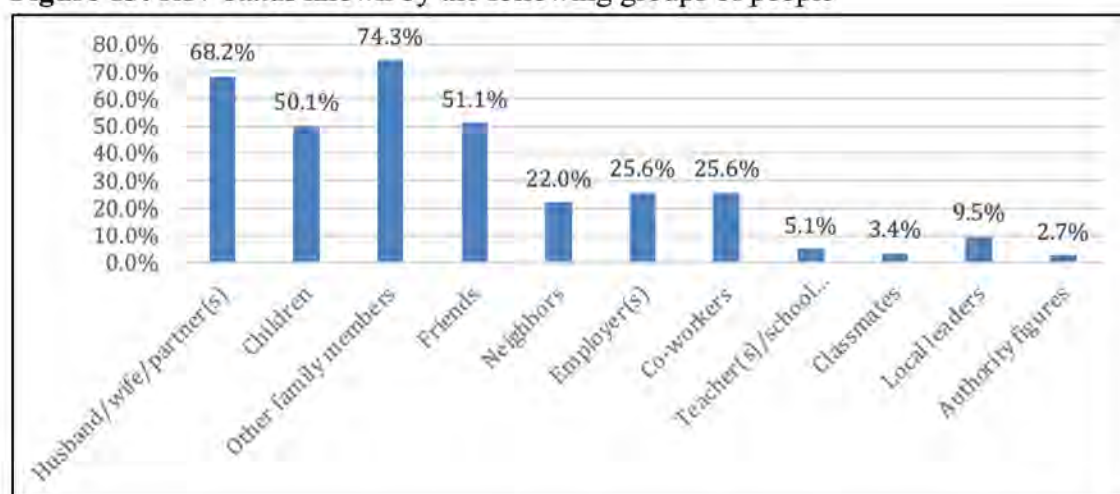
The study observed that most of the participants did not disclose their HIV when they went for non-HIV related healthcare services. 65.6 per cent of the sample (n=1,315) generally did not disclose their HIV status when seeking general (non-HIV related) health services, compared to 34.4 per cent (n=690) who did disclose their HIV status. In the qualitative interviews, participants argued that they did not find it easy to disclose their status and often did not do so unless it was necessary.

**Figure 12: Disclosure of HIV status when seeking general healthcare services, n=2,005**



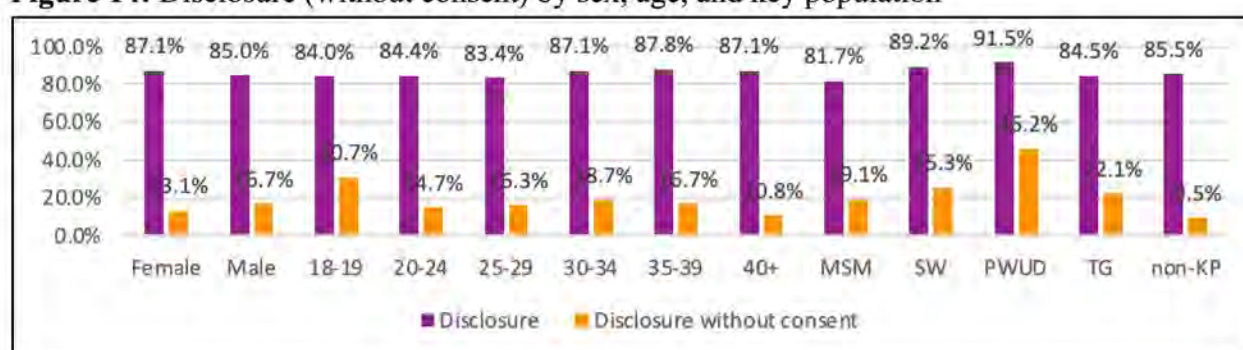
Participants were asked whether certain groups of people knew about their HIV status. Overall, 86.2 per cent of the participants indicated that at least one of the groups was aware of their HIV status as can be seen in Figure 13. Disclosure of HIV status by participants was higher to other family members (74.3%), followed by partners (68.2%) and friends (51.1%), whereas disclosure was lower at 5.1 per cent to teachers and classmates (3.4%).

**Figure 13: HIV status known by the following groups of people**



Disclosure without consent was experienced more often by those aged 18-19 years old (31.0%) compared to 10.8 per cent for those above 40 years old. Disclosure without consent was generally higher among key populations with the highest at 46.2 per cent among people who use drugs.

**Figure 14: Disclosure (without consent) by sex, age, and key population**



The participants were asked several questions relating to their experiences with HIV status disclosure. Overall, most participants (61.9%) agreed with the statement that disclosure of their HIV status to people they were close to had been a positive experience, compared to 23.0 per cent who somewhat agreed and 15.1 per cent who disagreed with this statement. When asked if people they were close to were supportive when first learning about their HIV status, 62.5 per cent agreed with the statement, 21.0 per cent somewhat agreed and 16.5 per cent disagreed. Contrary to the findings on disclosure to close associates, when asked if disclosure to people the participants did not know very well had been a positive experience, most participants disagreed with the statement (63.8%), with 18.3 per cent agreeing and 17.9 per cent somewhat agreeing. Similar findings are observed when participants were asked if people, they did not know very well were supportive when first learning about their HIV status, 65.1 per cent disagreed, with 16.1 per cent agreeing and 18.8 per cent somewhat agreeing. Lastly, 44.1 per cent of participants agreed that disclosure of HIV status had become easier over time, while 24.7 per cent somewhat agreed and 31.3 per cent disagreed. No major differences in experiences were observed between men and women.

### 3.3 Experiences of external stigma and discrimination

This section of the report presents results on levels and experiences of external stigma and discrimination and the effects of these experiences on the lives of people living with HIV who participated in the study. It covers stigma-based exclusions from social practices, including back-

biting and gossip, harassment, barriers to employment and economic activity and household experiences of stigma.

Participants were asked whether they had experienced certain types of external stigma and discrimination (indicated in the table below) because of their HIV status. Overall, 29.1 per cent of participants had at least one of these experiences within the last 12 months, with 51.7 per cent ever experiencing this. Taking a closer look, we see that 51.8 per cent of women had ever experienced discrimination versus 51.5 per cent of men; 61.8 per cent of gay men and other MSM, 70.7 per cent of sex workers; 78.3 per cent of PWUD; and 68.1 per cent of transgender people, versus 44.3 per cent of non-KP participants. A breakdown of the frequencies of each experience asked about can be found in Table 5 and Table 6 shows a further breakdown by key and vulnerable population.

**Figure 15:** Experience of stigma and discrimination in the last 12 months and ever, by sex, age, and key population

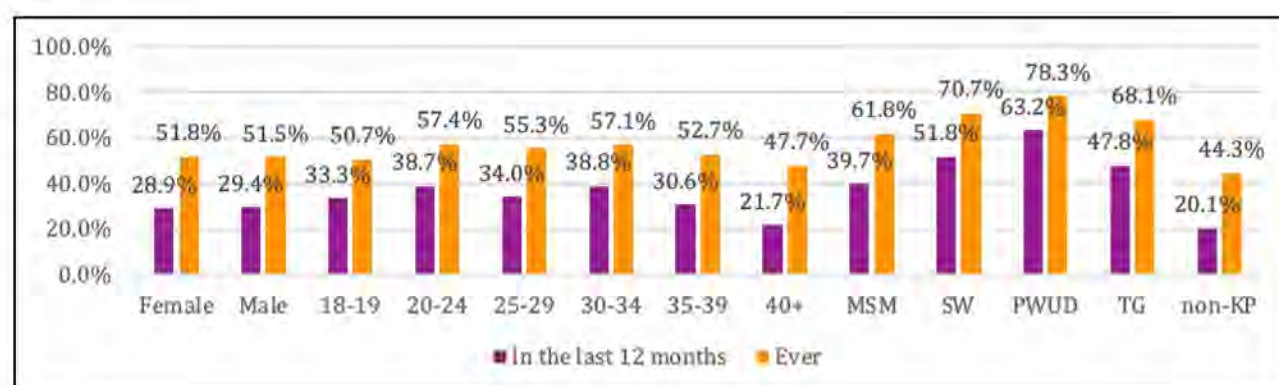


**Table 5:** Stigma and discrimination in the last 12 months and ever experience

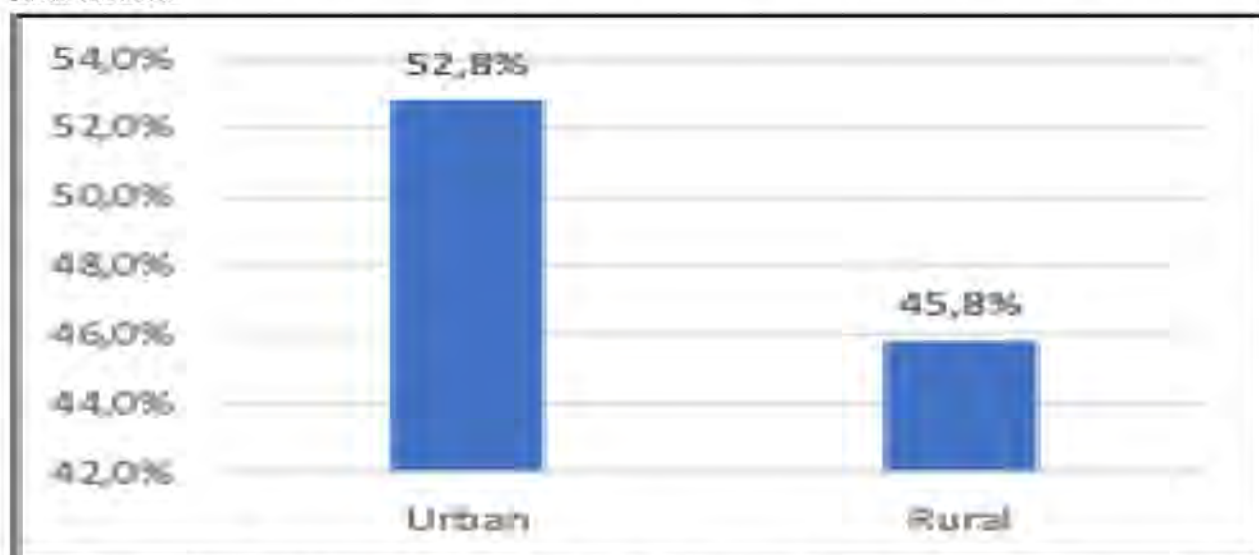
|                                                                                                              | In the last 12 months<br>n (%) | Ever<br>n (%) |
|--------------------------------------------------------------------------------------------------------------|--------------------------------|---------------|
| Exclusion from social gatherings or activities (e.g., weddings, funerals, parties, clubs)                    | 119 (6.1%)                     | 261 (13.3%)   |
| Exclusion from religious activities or places of worship                                                     | 38 (2.0%)                      | 75 (3.9%)     |
| Excluded from family activities                                                                              | 111 (5.6%)                     | 246 (12.5%)   |
| Awareness of family members making discriminatory remarks or gossiping about you                             | 288 (14.6%)                    | 624 (31.6%)   |
| Awareness of other people (other than family members) making discriminatory remarks or gossiping about you   | 341 (17.5%)                    | 696 (35.7%)   |
| Verbal harassment (e.g., yelled, scolded or was otherwise verbally abusive)                                  | 242 (12.2%)                    | 466 (24.0%)   |
| Blackmail                                                                                                    | 91 (4.6%)                      | 191 (9.6%)    |
| Physical harassment (e.g., pushed, hit or was otherwise physically abusive)                                  | 86 (4.3%)                      | 176 (8.9%)    |
| Refused employment or lost a source of income or job                                                         | 43 (2.4%)                      | 131 (7.2%)    |
| Change in job description or nature of the job or denied a promotion                                         | 26 (1.7%)                      | 65 (4.1%)     |
| Discrimination experienced by wife/husband, partner(s) or child(ren) because of the participants' HIV status | 122 (6.7%)                     | 249 (13.6%)   |

**Table 6:** Stigma and discrimination ever experienced in community settings, by key and vulnerable population

|                                                                                                              | MSM<br>n (%)  | SW<br>n (%)    | PWUD<br>n (%) | TG<br>n (%)   | PLHIV who have<br>ever interrupted<br>treatment<br>stopped/<br>HIV<br>n (%) |
|--------------------------------------------------------------------------------------------------------------|---------------|----------------|---------------|---------------|-----------------------------------------------------------------------------|
| Exclusion from social gatherings or activities                                                               | 30<br>(23.1%) | 119<br>(24.1%) | 33<br>(31.7%) | 21<br>(18.6%) | 25 (14.8%)                                                                  |
| Exclusion from religious activities or places of worship                                                     | 11 (8.6%)     | 38<br>(7.9%)   | 7<br>(6.7%)   | 7<br>(6.3%)   | 6 (3.6%)                                                                    |
| Excluded from family activities                                                                              | 30<br>(22.9%) | 115<br>(23.1%) | 41<br>(38.7%) | 27<br>(23.9%) | 24 (14.0%)                                                                  |
| Awareness of family members making discriminatory remarks or gossiping about you                             | 59<br>(45.4%) | 237<br>(47.6%) | 71<br>(67.0%) | 57<br>(50.4%) | 50 (28.4%)                                                                  |
| Awareness of other people (other than family members) making discriminatory remarks or gossiping about you   | 54<br>(41.5%) | 263<br>(53.4%) | 68<br>(64.8%) | 59<br>(52.7%) | 57 (34.1%)                                                                  |
| Verbal harassment                                                                                            | 41<br>(31.3%) | 202<br>(40.5%) | 50<br>(47.6%) | 38<br>(33.6%) | 38 (21.8%)                                                                  |
| Blackmail                                                                                                    | 25<br>(19.2%) | 95<br>(19.0%)  | 40<br>(37.7%) | 22<br>(19.5%) | 17 (9.6%)                                                                   |
| Physical harassment                                                                                          | 21<br>(16.0%) | 82<br>(16.4%)  | 18<br>(17.0%) | 19<br>(17.1%) | 12 (6.8%)                                                                   |
| Refused employment or lost a source of income or job                                                         | 15<br>(11.9%) | 49<br>(10.5%)  | 14<br>(16.1%) | 10<br>(9.9%)  | 8 (5.1%)                                                                    |
| Change in job description or nature of the job or denied a promotion                                         | 10 (8.5%)     | 28<br>(6.5%)   | 6<br>(7.6%)   | 4<br>(4.6%)   | 2 (1.5%)                                                                    |
| Discrimination experienced by wife/husband, partner(s) or child(ren) because of the participants' HIV status | 24<br>(20.3%) | 114<br>(24.3%) | 50<br>(49.0%) | 31<br>(29.8%) | 19 (12.3%)                                                                  |

Experiences of stigma and discrimination in general/community settings by urban and rural districts was noted to be higher in urban settings (52.8%) than in rural settings (45.8%).

**Figure 16:** Experience of stigma and discrimination in general/community settings by urban and rural districts



\* Rural areas include: Mpulungu, Nakonde, Katete, Mkushi, Sinazongwe, Mpongwe, Nchelenge, Chirundu, Mumbwa, Sasheke, Mwinilunga

\*\* Urban areas include: Mazabuka, Mansa, Mongu, Chingola, Kasama, Kafue, Kabwe, Livingstone, Kitwe, Lusaka, Chipata, Mpika, Kapiri Mposhi, Solwezi

Qualitative data supports the findings of the quantitative analysis, as the interview data shows that most interviewees had not experienced being refused employment or losing a source of income or job because of their HIV status. As the participants below explained, the question of status had never come up as a determinant to being employed. Because people did not know about their HIV status, they could not treat the PLHIV in a specific way because of their HIV status:

*"No one has ever discriminated against me because I have never told them, I do not tell anyone about my status." (Female Sex Worker- 28 years old)*

*Specifically, as the quotation below illustrates, the qualitative data shows matching evidence of stigma against transgender people. A transgender person from Kabwe, who singled out their classroom environment as particularly toxic, remarked as follows:*

*"You know we are a lot in class. Not everyone in my class understands [to belong to a rainbow community] so some treat me bad, some understand me, some do not understand me but the friends that I have around me they understand me and they have really helped me to live a positive life." (Transgender – 20 years old)*

Regarding employment, for example, and which points to the findings on disclosure, participants argued that they could not experience discrimination at the workplace or be denied employment opportunities because they had not disclosed their status to anyone. Because people did not know about their HIV status, they could not treat them in a specific way due to their status.

### 3.4 Internalised Stigma and Resilience

This section of the report focuses on experiences of participants with internalised stigma, its effects and actions taken.

Participants were asked multiple questions regarding internalised stigma in relation to self-confidence, self-respect, ability to respect others, ability to cope with stress, ability to have close

and secure relationships, ability to find love, ability to achieve personal goals and ability to practise a religion.

About 26.7 per cent reported a negative impact on their self-confidence resulting from their HIV status and 25.6 per cent reported that their ability to cope with stress had been negatively affected by their HIV status.

The study also revealed that 20.8 per cent of participants reported that their ability to have close and secure relationships had been negatively affected by their HIV status, while 26.5 per cent reported that their HIV status had negatively affected their ability to find love. A proportion of 22.6 per cent reported that their HIV status had negatively affected their desire to have children and 11.7 per cent reported that their HIV status had negatively affected their ability to contribute to their community.

In terms of achieving personal goals, 15.8 per cent of the participants reported that their HIV status had negatively affected their ability to achieve personal goals. The proportions of participants positively affected by the variables in this section ranged from eight per cent to 11 per cent.

The table below provides responses of the participants on whether certain needs had been positively affected, not affected or negatively affected by their HIV status in the last 12 months.

**Table 7:** Needs affected by HIV status in the last 12 months

|                                                       | Positively affected<br>n (%) | Not affected<br>n (%) | Negatively affected<br>n (%) |
|-------------------------------------------------------|------------------------------|-----------------------|------------------------------|
| Self-confidence                                       | 215 (10.7%)                  | 1252 (62.5%)          | 535 (26.7%)                  |
| Self-respect                                          | 161 (8.0%)                   | 1467 (73.3%)          | 374 (18.7%)                  |
| Ability to respect others                             | 196 (9.8%)                   | 1636 (81.6%)          | 172 (8.6%)                   |
| Ability to cope with stress                           | 213 (10.6%)                  | 1278 (63.7%)          | 514 (25.6%)                  |
| Ability to have close relationships with others       | 226 (11.3%)                  | 1355 (67.9%)          | 416 (20.8%)                  |
| Ability to find love                                  | 213 (11.0%)                  | 1216 (62.5%)          | 516 (26.5%)                  |
| Desire to have children                               | 179 (9.5%)                   | 1275 (67.9%)          | 435 (22.6%)                  |
| Ability to achieve personal and/or professional goals | 166 (8.5%)                   | 1479 (75.7%)          | 309 (15.8%)                  |
| Ability to contribute to the community                | 166 (8.3%)                   | 1592 (80.0%)          | 233 (11.7%)                  |
| Ability to practice a religion/faith                  | 201 (10.1%)                  | 1624 (81.5%)          | 168 (8.4%)                   |

The internalised stigma of the participants was also assessed. Participants were asked to indicate whether they had taken any actions because of their HIV status in the last 12 months (Table 8). A total of 16.9 per cent of the participants indicated that they decided not to have sex; 13.8 per cent isolated themselves from family and friends; 12.5 per cent chose not to attend social gatherings; and 12.1 per cent avoided going to the clinic or hospital when they needed to. The study also revealed that internalised stigma was generally higher among key populations, with PWUD experiencing more stigma with 37.7 per cent isolating themselves from family and/or friends; 37.3 per cent choosing not to attend social gatherings; and 35.9 per cent avoiding going to a clinic or hospital.

**Table 8:** Actions taken due to HIV internalised stigma

|                                                          | Yes<br>n (%) |
|----------------------------------------------------------|--------------|
| I have chosen not to attend social gatherings            | 248 (12.5%)  |
| I avoided going to a clinic or hospital when I needed to | 241 (12.1%)  |
| I have chosen not to apply for a job(s)                  | 88 (4.8%)    |
| I have chosen not to seek social support                 | 170 (8.5%)   |
| I have isolated myself from family and/or friends        | 276 (13.8%)  |
| I decided not to have sex                                | 326 (16.9%)  |

**Table 9:** Actions taken due to HIV internalized stigma, by key population

|                                                          | Yes, n (%) |       |       |       |        |
|----------------------------------------------------------|------------|-------|-------|-------|--------|
|                                                          | MSM        | SW    | PWUD  | TG    | Non-KP |
| I have chosen not to attend social gatherings            | 23.9%      | 23.7% | 37.3% | 15.3% | 7.8%   |
| I avoided going to a clinic or hospital when I needed to | 28.2%      | 24.5% | 35.9% | 26.1% | 6.3%   |
| I have chosen not to apply for a job(s)                  | 4.7%       | 7.9%  | 7.5%  | 6.6%  | 3.7%   |
| I have chosen not to seek social support                 | 16.8%      | 16.4% | 28.3% | 15.2% | 4.9%   |
| I have isolated myself from family and/or friends        | 26.7%      | 28.1% | 37.7% | 25.9% | 8.2%   |
| I decided not to have sex                                | 13.0%      | 16.4% | 12.4% | 14.3% | 17.5%  |

In addition, participants were asked if they agreed or disagreed with a set of statements related to internalised stigma because of their HIV status (Table 10). The study results indicated that 52.2 per cent agreed with the statement that they sometimes felt worthless because they were HIV positive; 49.8 per cent agreed with the statement that they were ashamed of being HIV+ and 21.7 per cent felt that being HIV positive made them feel dirty.

**Table 10:** Agreement with statements related to HIV internalized stigma

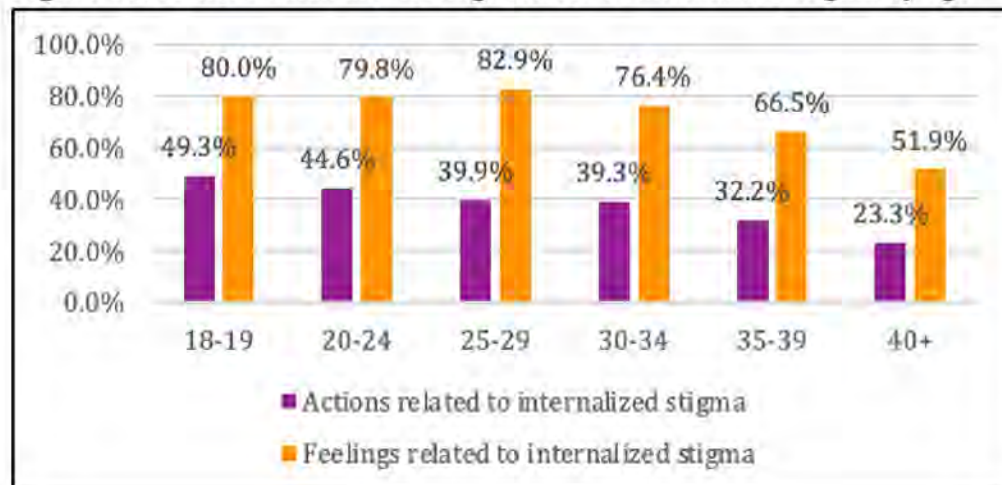
|                                                       | Agree<br>n (%) |
|-------------------------------------------------------|----------------|
| It is difficult to tell people that I am HIV positive | 215 (10.7%)    |
| Being HIV positive makes me feel dirty                | 436 (21.7%)    |
| I feel guilty that I am HIV positive                  | 362 (18.1%)    |
| I am ashamed that I am HIV positive                   | 998 (49.8%)    |
| I sometimes feel worthless because I am HIV positive  | 1050 (52.2%)   |
| I hide my HIV status from others                      | 430 (21.4%)    |

When disaggregating these findings by key populations, higher agreement with these statements related to HIV internalised stigma were observed for all participants that were part of a key population group, than for non-key population participants, with highest values among PWUD.

**Table 11:** Agreement with statements related to HIV internalized stigma, by key population

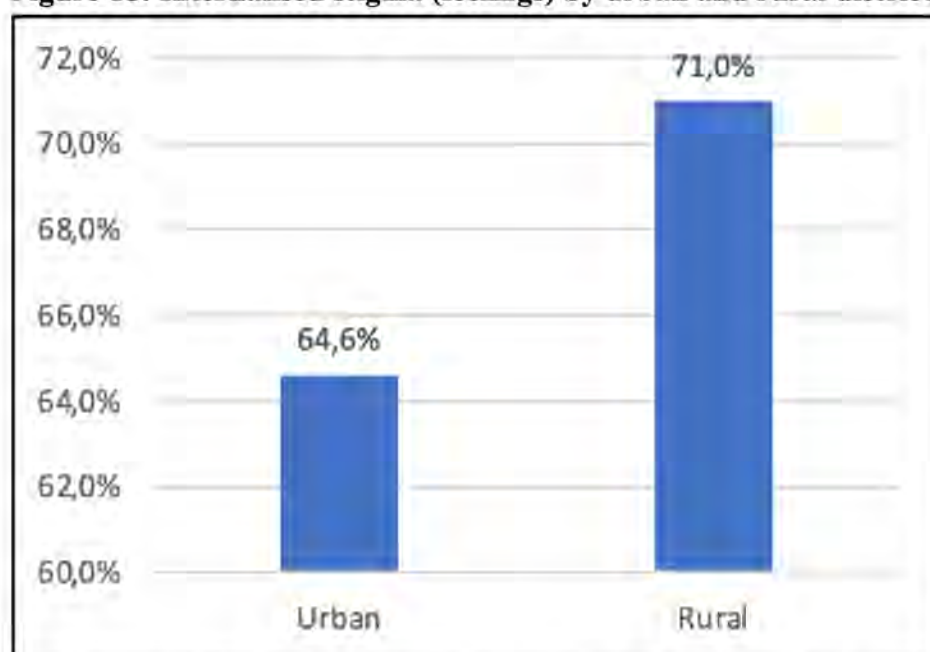
|                                                       | Yes<br>n (%) |       |       |       |        |
|-------------------------------------------------------|--------------|-------|-------|-------|--------|
|                                                       | MSM          | SW    | PWUD  | TG    | Non-KP |
| It is difficult to tell people that I am HIV positive | 13.0%        | 18.2% | 30.2% | 15.9% | 7.6%   |
| Being HIV positive makes me feel dirty                | 32.1%        | 34.9% | 49.1% | 30.2% | 16.3%  |
| I feel guilty that I am HIV positive                  | 23.7%        | 29.1% | 38.7% | 27.4% | 13.7%  |
| I am ashamed that I am HIV positive                   | 61.8%        | 63.4% | 70.8% | 62.0% | 44.5%  |
| I sometimes feel worthless because I am HIV positive  | 58.8%        | 65.1% | 71.7% | 63.7% | 47.5%  |
| I hide my HIV status from others                      | 31.3%        | 32.9% | 43.8% | 34.5% | 16.8%  |

Overall, 32.2 per cent had taken at least one of the actions listed in Table 8 and 65.5 per cent agreed with at least one of the statements listed in Table 10. Generally, it can be observed that both actions and feelings related to internalised stigma seemed to go down with age (Figure 17), indicating that internalised stigma was more common amongst younger people. In addition, those who had taken actions or experienced feelings related to internalised stigma were found to more frequently interrupt or stop their HIV treatment (versus those who did not take such actions or experience such feelings), with 51.9 per cent versus 23.3 per cent for actions related to internalised stigma and 82.9 per cent versus 51.9 per cent for feelings related to internalised stigma.

**Figure 17:** Actions taken and feelings related to internalised stigma by age

Experiences of internalised stigma were higher in rural settings (71%) compared to urban settings (64.6%).

**Figure 18: Internalised stigma (feelings) by urban and rural districts**



\* Rural areas include: Mpulungu, Nakonde, Katete, Mkushi, Sinazongwe, Mpongwe, Nchelenge, Chirundu, Mumbwa, Sasheke, Mwinilunga

\*\* Urban areas include: Mazabuka, Mansa, Mongu, Chingola, Kasama, Kafue, Kabwe, Livingstone, Kitwe, Lusaka, Chipata, Mpika, Kapiri Mposhi, Solwezi

### 3.5 Interactions with Healthcare Services

This section presents findings on health care services focusing on the variables on HIV information; peer support; prevention services and commodities; HIV treatment services; case management; and HIV care and testing services.

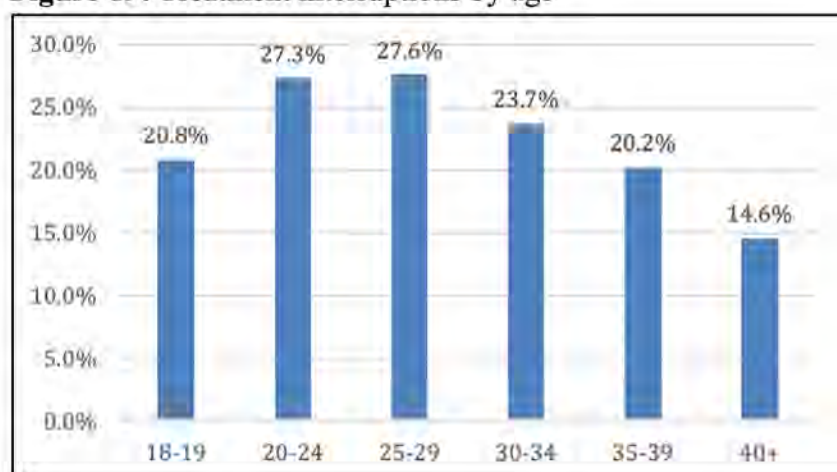
In relation to access to services 90 per cent of the participants reported to be or ever been on HIV treatment. The analysis highlights minor differences between men and women in terms of their engagement with healthcare services, with 89.9 per cent of men and 91.5 per cent of women being on or ever been on HIV treatment. Overall, 19.7 per cent of the participants had ever interrupted or stopped their HIV treatment. Of those who had ever interrupted or stopped their treatment, the most common reason was concern over someone else discovering their HIV status (55.4%). This key factor emerged as the predominant explanation, as indicated in Table 12 below.

**Table 12: Main reasons for treatment interruptions**

|                                                                                                       | n (%)       |
|-------------------------------------------------------------------------------------------------------|-------------|
| I am worried that someone would find out my HIV status                                                | 174 (55.4%) |
| I am worried the healthcare workers would treat me badly or disclose my HIV status without my consent | 11 (3.5%)   |
| I was denied HIV treatment due to currently using drugs                                               | 2 (0.6%)    |
| I am not ready to deal with my HIV infection                                                          | 35 (11.2%)  |
| Other reason                                                                                          | 92 (29.3%)  |

Figure 19 below shows that treatment interruptions were most frequent among those aged between 20 to 24 years (27.3 per cent in the age group 20-24 ever interrupted the treatment) and 25 to 30 years (27.6 per cent in the age group 25-30 ever interrupted the treatment).

**Figure 19: Treatment interruptions by age**



Additionally, the quotation provided below, from a female sex worker indicates that concerns about the size of the medication tablets also played a role in the decision-making process, further complicating the individuals' ability to adhere to the prescribed treatment regimen:

*"I am HIV positive but and I am not on treatment because I just do not want to. I hear they will bring injectable ARVs. That is what am waiting for. I cannot make it everyday tablets; it is difficult yes. I failed to swallow. The tablet is too big, and I fear to be seen. This has made me not being active in everything I want to do in my life. I would just want them to bring ARVs injections for positive people." (FSW, 30 years old)*

The qualitative analysis shows that there are specific barriers to care, especially among key populations. MSM participants, for example, argued that they hesitated or thought twice before visiting a health centre to seek treatment because of public attitudes and the nation's legal position towards MSM (criminalisation). This was captured in the quotation from an 18-year-old, who is currently in school and exposed to various forms of information. In the following quotation, (MSM,18) explains how sometimes he is scared to go to a governmental hospital for his medication because he is not sure what might happen to him. While this has the immediate implication that sometimes he misses treatment days, it also highlights a state of fear (that he may be arrested), which negatively impacts upon his mental health:

*"Yeah, most of the time the challenges that I face are you find I would want to go to maybe a clinic and tell them that I need medication [be]cause my orientation is KP, so, meaning... I MSM, it's very difficult for me to seek proper treatment at a government clinic and be free because it's not legal in Zambia. So, that is one of the challenges I have in accessing health care. In situations where I don't have transport most of the times, I have to stay without taking medicine you find that the same day I have to go and collect the drugs I don't take maybe it will take me another twenty-four hours without taking medicine and also being key pop is somehow a problem when it comes to government clinics so sometimes am not free to go and seek treatment because am not sure what can happen. (MSM, 18 years old)*

Most the participants usually received their HIV care and treatment in government clinics (80.9%), followed by non-governmental clinics (11.4%). In addition, when asked about knowledge of community-led clinics that provided HIV services, 17.7 per cent stated being aware of such clinics and accessing their HIV care there and 39.2 per cent were aware of such clinics but did not access their HIV care there. When these participants were asked about knowledge of which types of

services they could access in the community-led clinics, they indicated awareness of the services in table 13 below.

**Table 13:** Knowledge of access to HIV-related services in community-led clinics

| Type of service                     | n (%)         |
|-------------------------------------|---------------|
| HIV information                     | 1,037 (91.3%) |
| Peer support (groups)               | 686 (60.4%)   |
| Adherence counselling               | 924 (81.3%)   |
| Prevention services and commodities | 759 (68.8%)   |
| HIV treatment services              | 867 (76.3%)   |
| Case management                     | 1037 (91.3%)  |
| HIV care and testing services       | 686 (60.4%)   |

Participants were also asked if their most recent viral load test in the last 12 months showed they had an undetectable viral load, 71 per cent of participants indicated they had an undetectable viral load. However, 6.0 per cent had not had a viral load test in the last 12 months, 11.9 per cent had a viral load test and were still waiting for the results, 8.4 per cent indicated the results showed the virus was detectable and 1.3 per cent had never had a viral load test. In addition, 1.4 per cent indicated that they did not know what viral load or viral suppression were. Moreover, results showed that 77.7 per cent of the participants were sure that their medical records related to HIV were kept confidential and would not be shared without their written informed consent. However, 19.6 per cent did not know if their medical records were kept confidential or not and 2.7 per cent stated that it was clear to them that their medical records were not being kept confidential.

Participants who had sought HIV specific healthcare in the past 12 months reported experiencing some form of stigma and discrimination by healthcare workers due to the participants' HIV status.

**Table 14:** Forms of stigma and discrimination experienced from healthcare facility in the past 12 months

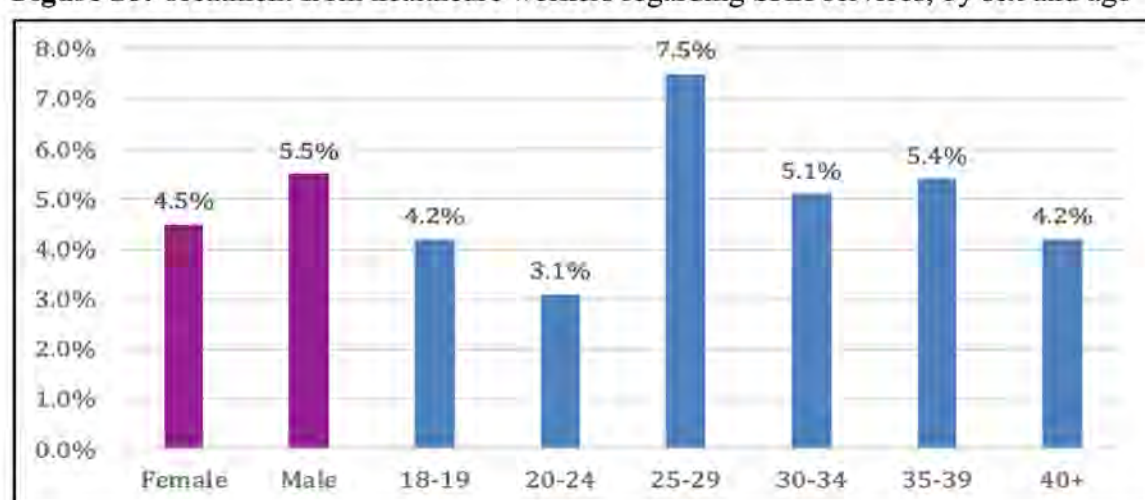
|                                                        | n (%)      |
|--------------------------------------------------------|------------|
| Being denied health services                           | 35 (1.8%)  |
| Being advised not to have sex                          | 120 (6.1%) |
| Being talked badly about or gossiped about             | 164 (8.4%) |
| Verbal abuse                                           | 152 (7.8%) |
| Physical abuse                                         | 44 (2.3%)  |
| Avoidance of physical contact/taking extra precautions | 104 (5.3%) |
| Telling people about your HIV status without consent   | 129 (6.6%) |

In the last 12 months, participants reported having received treatment indicated in table 15 from healthcare workers, solely because of their HIV status, regarding Sexual and Reproductive Health (SRH).

**Table 15:** Treatment from healthcare workers regarding SRH services

|                                                                                                                       | n (%)     |
|-----------------------------------------------------------------------------------------------------------------------|-----------|
| Advised you not to mother/father a child                                                                              | 46 (2.5%) |
| Pressured or incentivised you to get sterilised                                                                       | 15 (0.8%) |
| Sterilised you without your knowledge or consent                                                                      | 11 (0.6%) |
| Denied your contraception/family planning services                                                                    | 23 (1.3%) |
| Told you that you had to use (a specific method of) contraception in order to get your HIV (antiretroviral) treatment | 28 (1.6%) |

Results showed that 5.5 per cent of men and 4.5 per cent of women had at least one of these experiences. People in age group 25-29 most often (7.5%) experienced such treatment. See figure 20 below.

**Figure 20:** Treatment from healthcare workers regarding SRH services, by sex and age

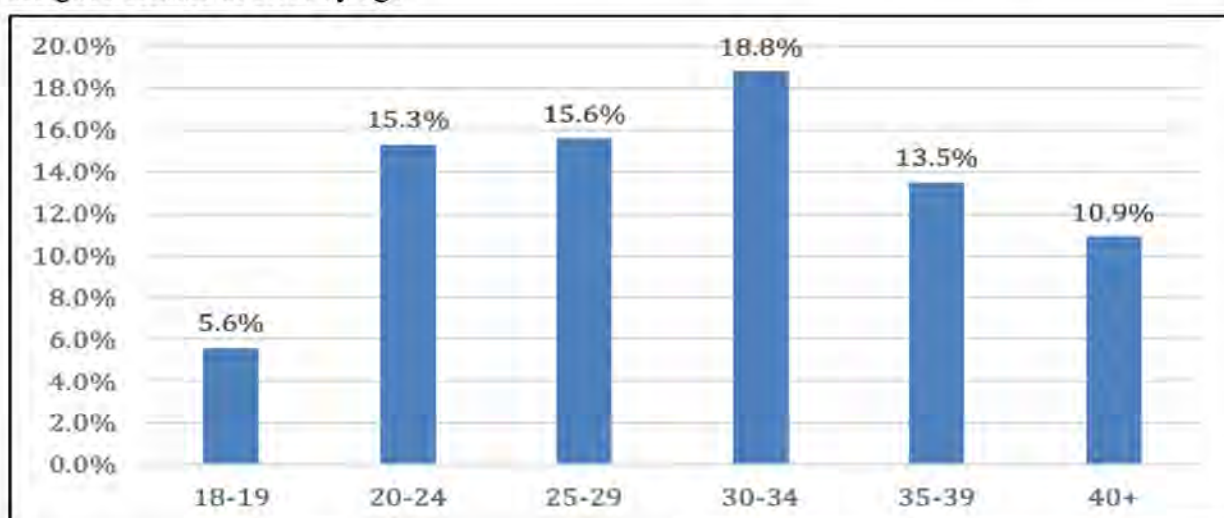
People who were assigned female at birth (n=1,228) were asked an additional set of questions regarding SRH, which showed the results tabulated in table 16.

**Table 16:** Treatment from healthcare workers regarding SRH services by people who were assigned female at birth

|                                                                          | Yes, within the last 12 months<br>n (%) | Ever<br>n (%) |
|--------------------------------------------------------------------------|-----------------------------------------|---------------|
| Advised you to terminate a pregnancy                                     | 3 (0.3%)                                | 12 (1.1%)     |
| Pressured you to use a specific type of contraceptive method             | 21 (1.8%)                               | 43 (3.7%)     |
| Pressured you to use a particular method of giving birth/delivery option | 35 (3.2%)                               | 104 (9.6%)    |
| Pressured you to use a particular infant feeding practice                | 15 (1.4%)                               | 44 (4.1%)     |
| Pressured you to take HIV (antiretroviral) treatment during pregnancy    | 17 (1.6%)                               | 55 (5.3%)     |

If we take a closer look at this, it can be observed that people who were assigned female at birth in age group 30-34 (18.8%) experienced such treatment most often. See figure 21 below.

**Figure 21:** Treatment from healthcare workers regarding SRH services experienced by people assigned female at birth by age

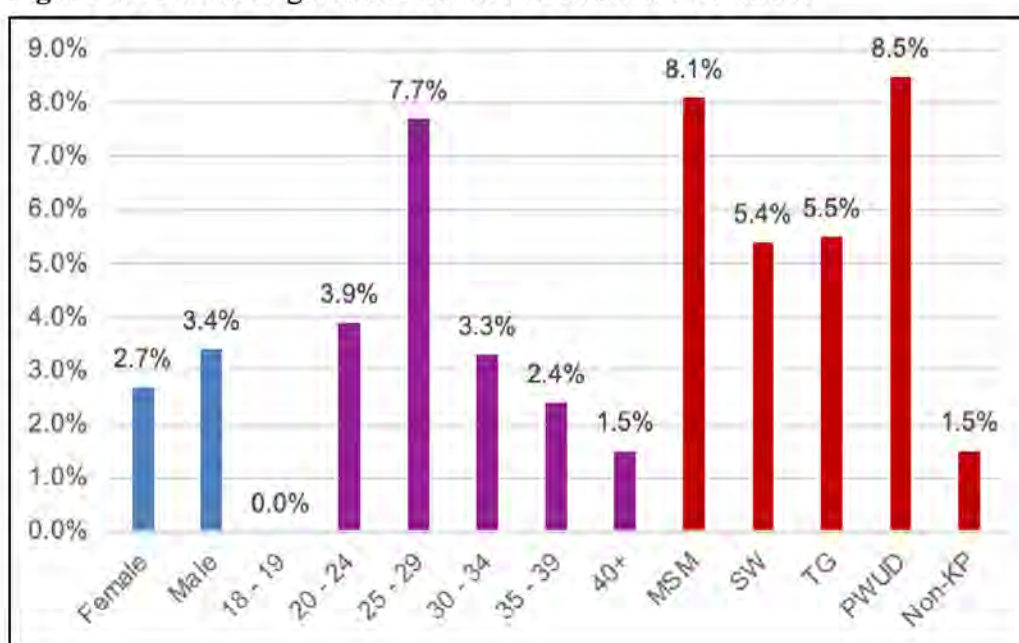


### 3.6 Human Rights and Affecting Change

Participants were asked their knowledge of laws safeguarding people living with HIV from stigma and discrimination in Zambia. About 54.1 per cent of the participants were aware that there are national laws that protect PLHIV from stigma and discrimination, while 3.8 per cent stated there were no such laws and 42.1 per cent did not know if there were laws that protected PLHIV from stigma and discrimination or not.

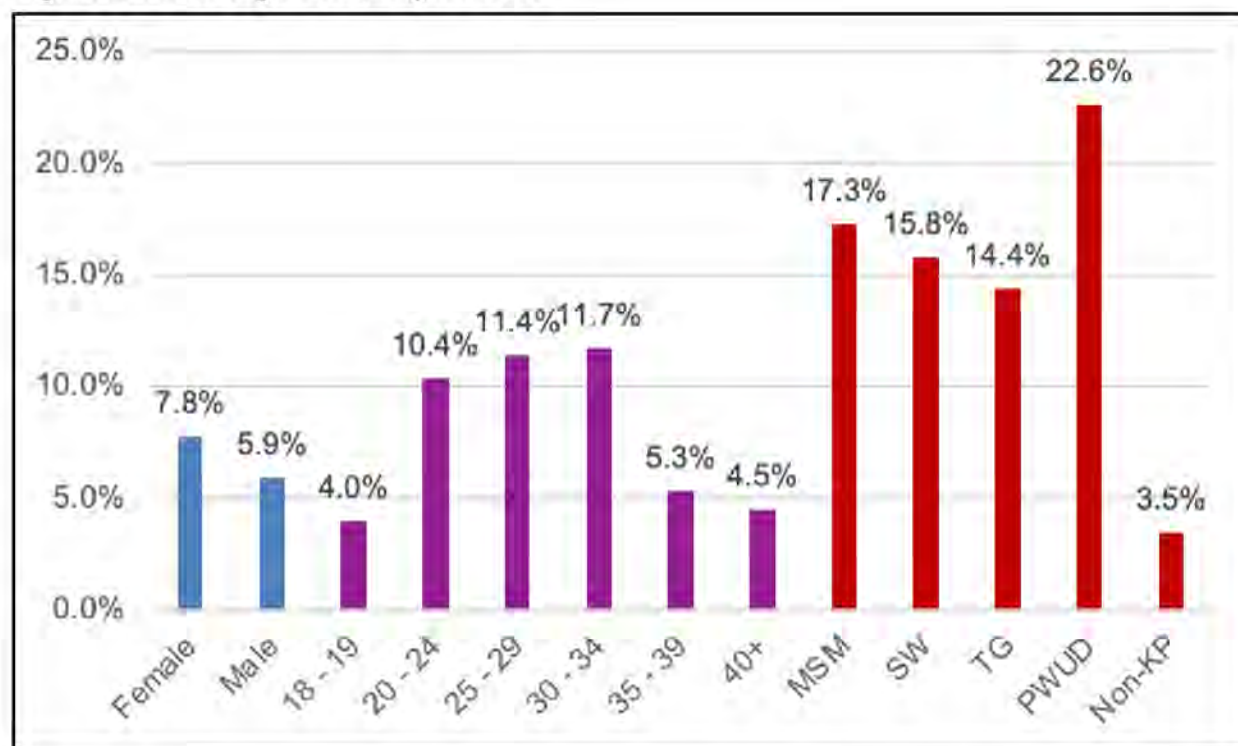
The participants were asked if they were ever forced to get tested for HIV or disclose their status in order to obtain a visa or apply for a residency/citizenship in a country; apply for a job or pension plan; attend an educational institution or get a scholarship; get health services; or get medical insurance. While there were no major differences in terms of sex, those aged between 25-29 years were most often forced to get tested for HIV or disclosure their status (Figure 22). In addition, all key population groups experienced this more often than those who are not part of key population.

**Figure 22:** Forced to get tested for HIV or disclose HIV status



The experience of other types of rights abuses was also assessed. No major sex or age-related differences were observed. However, those who were part of a key population more often reported to have ever experienced at least one of the rights abuses asked about (Figure 23).

**Figure 23:** Ever experienced rights abuse



Of participants who had experienced any rights abuses in the last 12 months, 29.5 per cent indicated attempting to do something about the matter, while 70.5 per cent did not. When asked about the results of acting against the rights abuses experienced, over half of the participants (58.6%) reported that the matter had been dealt with. For 3.8 per cent of participants, the matter was still in the process of being dealt with and 32.8 per cent of participants reported that nothing had happened or that the matter was not dealt with.

The participants were asked about any actions they have taken to affect change in relation to stigma and discrimination. Actions most often taken by the participants were challenging or educating someone who was engaging in stigma and discrimination against other people living with HIV (56.1%, n=1, 124), followed by providing emotional, financial, or other support to help someone living with HIV deal with stigma and/or discrimination (53.4%, n=1072) (Table 17).

**Table 17:** Actions taken to affect change within the last 12 months and ever (response option No is not being shown)

|                                                                                                                                        | Within the last 12 months<br>n (%) | Ever<br>n (%) |
|----------------------------------------------------------------------------------------------------------------------------------------|------------------------------------|---------------|
| Challenged or educated someone who was engaging in stigma or discrimination against you                                                | 561 (28.0%)                        | 951 (47.4%)   |
| Challenged or educated someone who was engaging in stigma and discrimination against other people living with HIV                      | 665 (33.2%)                        | 1,124 (56.1%) |
| Provided emotional, financial or other support to help someone living with HIV deal with stigma and/or discrimination                  | 702 (35.0%)                        | 1,072 (53.4%) |
| Participated in an organisational or educational campaign working to address stigma and discrimination against people living with HIV  | 403 (20.1%)                        | 667 (33.3%)   |
| Encouraged a community leader to take action about issues of stigma and discrimination against people living with HIV                  | 242 (12.1%)                        | 313 (20.6%)   |
| Encouraged a government leader or a politician to take action about issues of stigma and discrimination against people living with HIV | 113 (5.6%)                         | 222 (11.1%)   |
| Spoke to the media about issues of stigma and discrimination against people living with HIV                                            | 72 (3.6%)                          | 162 (8.1%)    |

### 3.7 Stigma and Discrimination Experienced for Reasons other than HIV Status

All participants, who identified as part of a key population group, were also asked about any stigma and discrimination they may have experienced due to reasons other than their HIV status. Table 18 shows the findings on several different types of stigma and discrimination experienced due to being part of a key population group in the last 12 months.

**Table 18:** Stigma and discrimination experienced by key population in the last 12 months

|                                        | Transgender people<br>n=113 (%) | Gay men and other MSM<br>n=131 (%) | Sex workers<br>n=502 (%) | People who use drugs<br>n=106 (%) |
|----------------------------------------|---------------------------------|------------------------------------|--------------------------|-----------------------------------|
| Being excluded from family activities  | 29 (12.0%)                      | 15 (14.9%)                         | 148 (34.6%)              | 43 (40.6%)                        |
| Being gossiped about by family members | 34 (14.5%)                      | 26 (26.0%)                         | 150 (35.0%)              | 43 (40.6%)                        |
| Being afraid to seek health services   | 25 (10.6%)                      | 27 (25.2%)                         | 122 (28.5%)              | 41 (38.7%)                        |
| Avoided seeking health services        | 24 (10.4%)                      | 23 (21.7%)                         | 92 (21.3%)               | 38 (36.2%)                        |
| Experiencing verbal harassment         | 34 (14.6%)                      | 20 (19.1%)                         | 153 (35.2%)              | 42 (39.6%)                        |
| Experiencing blackmail                 | 25 (10.6%)                      | 14 (13.1%)                         | 84 (19.4%)               | 32 (30.2%)                        |
| Experiencing physical harassment       | 21 (8.9%)                       | 17 (16.2%)                         | 113 (26.3%)              | 33 (32.2%)                        |

Looking at the number of people who experienced at least one of these experiences of stigma and discrimination in the last 12 months, this was 22.7 per cent (n=62) for transgender people, 41.4 percent (n=44) for gay men and other MSM, 56.2 per cent (n=245) for sex workers and 61.3 percent

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(n=65) for people who use drugs. The number of people who have experienced stigma and discrimination due to belonging to a key population is even higher if we look at who has ever had at least one of these experiences: 37.4 per cent (n=102) of transgender people, 77.6 per cent (n=83) of gay men and other men who have sex with men, 71.8 per cent (n=313) of sex workers and 76.4 per cent (n=81) of people who use drugs.

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## 4.0 DISCUSSION

### 4.1 The participants

The findings indicate that, among the 2, 007 participants surveyed, 61.3 per cent were assigned female at birth and 38.7 per cent were assigned male at birth. This distribution aligns closely with the planned proportions based on national HIV statistics, reflecting the study's careful sampling methodology to ensure representation of individuals living with HIV in Zambia. Notably, the observed distribution mirrors the intended sample allocations of 62 per cent women and 38 per cent men, underscoring the study's adherence to its proposed methodology and enhancing its credibility to draw meaningful conclusions about the population of interest. It is noteworthy that some participants have undergone gender transition, with approximately 3.7 per cent identifying as transgender individuals, a proportion higher than the 0.6 per cent recorded in the 2012 Stigma Index. Additionally, 5.3 per cent disclosed being people who used drugs, while only 1.2 per cent identified as men who had sex with men (MSM). The study also identified 242 participants living with disabilities.

### 4.2 Ability to meet basic needs

The findings showed that 41.9 per cent of the participants were unemployed; 14.7 per cent in casual employment; and 17.7 per cent in part-time employment. The study further established that there was high prevalence of unemployment, aligning closely with national statistics, which reflects a high prevalence of informal employment within the national economy. For example, the Labour Force survey of 2021 estimated unemployment to be at 38.8 per cent of the working age population.<sup>11</sup> Further analysis revealed that there were twice as many women (n=568) represented in the unemployed category than there were men (n=271). The findings also highlighted the considerable difficulty experienced by the participants in meeting their basic needs (e.g., food, clothing, shelter) with only 10.7 per cent of participants always being able to meet their basic needs. This resonates with national statistics, which indicate that over half (54%) of the Zambian population live in poverty, defined in terms of material deprivation as inability to afford minimum basic human needs comprising food and non-food items within one's total income.<sup>12</sup> While the situation was dire for most participants, findings indicated that sex workers and people who use drugs are most affected by inability to meet basic needs. This is largely because of the low education status which has limited their opportunity to make gainful income.

### 4.3 Membership to support groups

Studies consistently show that the relational elements of support groups play a critical role in meeting the informational and psychosocial needs of people living with HIV. By offering a safe and understanding environment, support groups facilitate knowledge sharing, emotional support and response strategies. Hence, those individuals who belong to support groups tend to adhere to treatment, experience better health outcomes and quality of life overall. Exclusion from support networks and resources may lead to increased stress levels and potentially exacerbate disease progression.<sup>13</sup> While analysis of duration of knowledge of HIV status showed that most participants have known their HIV status for more than four years, most of the participants in this

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<sup>11</sup> Labour Force Survey Report of 2021. February 2022. The Zambia Statistics Agency. Government Printers, Lusaka.

<sup>12</sup> Zambia Statistics Agency (ZAMSTATS). 2015. Living Conditions Monitoring Survey Report. Lusaka

<sup>13</sup> Bateganya, M., Amanyeive, U., Roxo, U., & Dong, M. (2015). The impact of support groups for people living with HIV on clinical outcomes: a systematic review of the literature. *Journal of acquired immune deficiency syndromes (1999)*, 68(0 3), S368.; Peterson, J. L. (2009). "You have to be positive." Social support processes of an online support group for men living with HIV. *Communication Studies*, 60(5), 526-541.

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study, accounting for 61.7% of the sample (n=1238), did not belong to a network or support group for people living with HIV. It is also noteworthy that although Zambia had a national network of people living with HIV offering support groups for women living with HIV, there is no national network of women living with HIV. However, among the key population groups, there were more people who used drugs who belonged to a support group than there was anyone else. This finding raises concerns and underscores the pressing need for enhanced community engagement efforts. Research has consistently demonstrated that membership to support-groups yields more favourable health outcomes for individuals living with HIV. Therefore, it is imperative to prioritise the establishment and promotion of comprehensive support networks within the community. By fostering greater participation in support groups, current interventions can contribute to improved well-being and overall quality of life for people living with HIV.

#### **4.4 Disclosure**

The study observed that most of the participants did not disclose their HIV status when they went for general/non-HIV related health services. About 65.6 per cent of the sample (n=1,315) did not disclose their status compared to 34.4 per cent (n=690) who did. Various categories of participants had different disclosure experiences, with PWUD experiencing the highest disclosure without consent. Similarly, young people (18-19 years) experienced high levels of disclosure without consent (31%). On the other hand, young people were not keen to disclose their status to teachers and classmates. Qualitative data revealed that participants did not find it easy to disclose their status and this provided a broader context to their experiences of stigma. For example, even though most participants had not experienced stigma or discrimination from outside environment, they feared that if they disclosed, they would be stigmatised. Hence, against this evidence, it is reasonable to conclude that even though most participants had not experienced stigma and discrimination as actions towards them by others, they had a perception that people would stigmatise them if they knew their status. This fear was a form of internalised stigma. However, the findings demonstrate that, irrespective of sex, participants generally reported positive outcomes following disclosure of their HIV status to close acquaintances.

These findings shed light on the potential for supportive and understanding social networks, contributing to reduced stigma and improved well-being among individuals living with HIV. Regarding the findings on disclosure to people the participants were not close to, it demonstrated an opportunity for enhanced community awareness with messages that would foster understanding, acceptance and empathy towards individuals who were living with HIV. This would address discriminatory attitudes against people who are living with HIV. Nearly half of the participants (44.1%) indicated that disclosure had become easier over time. It is worth emphasising that the ease of disclosure can be influenced by various factors beyond the passage of time. Factors such as acceptance, support and positive experiences from both close and distant individuals played a significant role.

Consequently, while time is a noteworthy factor, other social, cultural and environmental aspects are crucial in shaping attitudes towards people living with HIV. These factors, in turn, determine the ease with which individuals living with HIV can openly disclose their status. Taking the results above altogether, close family members and the generalised other stood out as more accepting of people living with HIV. This signals a significant shift in attitudes towards people living with HIV. It also suggests an opportunity to strengthen programming around peer support in and around the family.

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## 4.5 Levels and experiences of stigma and discrimination

Overall, the findings showed a decline in external stigma and discrimination experiences compared to the 2012 study, although in some instances, it was higher than the 10-10-10 targets<sup>14</sup>. For example, one third of the participants in 2012 reported having experienced exclusion from social activities compared to 13.3 per cent in 2023. Similarly, 36 per cent of participants in 2012 reported being physically harassed or threatened compared to 8.9 per cent in 2023. One of the factors that may lead to low levels of external stigma could be attributed to non-disclosure of HIV status in public, which gives no basis for people to stigmatise.

## 4.6 Internalised stigma

Unlike external forms of stigma and discrimination, which were affecting smaller proportions of the study population, significantly more participants reported various forms of internalised stigma even though overall it has been observed that there is an increase in internalised stigma in 2023 compared to 2012 for some selected variables. The 2023 study reported the proportion of participants who felt ashamed of themselves was at 49.1 per cent while the proportion recorded in 2012 is 45.1 per cent, which shows an increase. However, there was a reduction from 44.1 per cent in 2012 to 18.1 per cent in 2023 regarding participants who felt guilty about being HIV positive. Generally, it was observed that both actions and feelings related to internalised stigma were more common amongst younger people 18 to 24 years compared to those 40 years and above. However, treatment interruptions were highest in the age group 20- 29 years.

The study shows a relationship between age and feeling ashamed because one has HIV, with higher proportions of those affected in the lower age bracket, 18-24 years olds recorded being ashamed of HIV status at about 80 per cent compared to 50 per cent among those 40 years old and above. Additionally, about 21 per cent of the sample reported that HIV had negatively affected their desire to have children. The study identified various factors contributing to self-stigma. Among KPs particularly, self-stigma is informed by fear arising from what they perceived as negative attitudes towards KP groups citing fear of going to a clinic or hospital and self-isolation. Overall, however, fear of public reaction to one's HIV status affected the participants to the extent that most participants did not disclose their status outside the HIV clinic. In specific instance, it affected adherence to treatment with some indicating that they stopped treatment for 'fear of being seen' preferring to wait until there were more discreet treatment alternatives. Notwithstanding the increase in internalised stigma, there was a reduction in psychosocial support interventions for young people and adults living with HIV.

## 4.7 Access to HIV treatment and Care Services

The findings presented showed that access to treatment nowadays has improved, decreasing general visibility of AIDS and improving quality of life. Against a backdrop of low disclosure, this may contribute to the low levels of external stigma and discrimination observed in this study. However, as demonstrated by the findings on disclosure and internalised stigma, which was more pronounced than external stigma, low disclosure in itself linked to high internalised stigma. Related to these experiences were the high levels of treatment interruptions, often due to fear of someone finding out their status – a manifestation of internalised stigma. These results underscore the significance of privacy concerns, non-acceptance of HIV status and the potential impact on treatment adherence. They underscore the multifaceted considerations and challenges faced by individuals living with HIV who opt not to pursue treatment. Additionally, access challenges observed in the study must be understood in the context of the overall structural barriers within the Zambian health system which

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<sup>14</sup> 2030 Ending the AIDS epidemic. UNAIDS.

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include the material deprivation (preventing people from going to health centres), poor distribution of health facilities as well as the variations of stigma and discrimination already discussed. However, even more importantly it shows the need for supportive systems that can assist individuals with information and address internalised stigma. Such interventions and support services to address the barriers to treatment initiation and adherence for people living with HIV are a matter of urgency.

#### **4.8 Human Rights and Affecting Change**

Results indicate that there were gaps in understanding rights and entitlements, including legal protections among PLHIV participants. While 54.1 per cent of the participants were aware that there were national laws that protected PLHIV from stigma and discrimination, 3.8 per cent stated that there were no such laws and 42.1 per cent did not know if there were such laws or not. Overall, 2.7 per cent of the participants assigned female at birth and 3.4 per cent of those assigned male at birth reported having been forced to get tested for HIV or disclose their HIV status. The findings are crucial in understanding the existing gaps in their knowledge regarding legal provisions established to protect people living with HIV from discrimination. Similar findings were stated in the 2017 report on the status of sexual and reproductive health and rights in Zambia. The report indicates progress in various aspects, yet persistent disparities exist particularly affecting women and girls in rural areas. Limited education contributes to their disadvantage, hindering access to essential information. Overall, significant gaps prevail in accessing both information and services related to contraception, attributed to supply constraints and gender stereotypes. Conversely, women in urban areas enjoyed better access to these services and were more empowered to seek justice for related violations.<sup>15</sup>

Overall, findings demonstrate the importance of addressing and closing the gaps in understanding to ensure that people living with HIV are fully informed about their rights and legal protections against discrimination, even though Zambian law criminalises same-sex relationships.<sup>16</sup> Efforts should be directed toward enhancing education and awareness initiatives to promote greater knowledge and comprehension of these legal safeguards. For example, Article 11 of the Republican Constitution emphasizes the fundamental rights and freedoms that every individual, including those living with HIV are entitled to. Anchoring the advocacy efforts on this constitutional provision will lend significant weight and impact to it. However, it should also be noted that wilful transmission of HIV is criminalised under Zambian law.

The evidence presented in this study yields several key observations. Firstly, it highlights heightened hardship among participants, with a majority experiencing unemployment and struggling to meet basic needs, a matter of significant concern given people's treatment regimes. The findings also underscore limited membership in support groups of people living with HIV and emphasize that disclosure of status remains a key challenge to most. The evidence presented shows a decline in external stigma since 2012 when the last Stigma Index was conducted, although, in some instances, the proportions surpass the set 10-10-10 targets. In contrast to external forms of stigma and discrimination, more participants reported various forms of internal stigma, albeit at levels lower than those observed in 2012. The research also notes increased access to treatment, while significant gaps persist in understanding rights, entitlements and legal protections among

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<sup>15</sup> Population Council, UNFPA, Government of Zambia Human Rights Commission, WLSA, and United Nations in Zambia. (2017). "The Status of Sexual and Reproductive Health and Rights in Zambia: Comprehensive Sexuality Education and Adolescents Sexual and Reproductive Health." Lusaka, Zambia.

<sup>16</sup> UNDP, National HIV/AIDS/STI/TB Council of Zambia (2019). Zambia: Legal Environment Assessment for HIV, TB, Sexual and Reproductive Health & Rights.

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participants. Although the samples of the key populations were small, affecting the generalisability of those findings, the inclusion of qualitative data enhances the depth of understanding that can be drawn from this study.

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## 5.0 CONCLUSION

This research has provided valuable evidence on stigma and discrimination faced by individuals living with HIV in Zambia. It has revealed the diversity of experiences and identities within the participant sample. Evidence has indicated varying levels of employment across different sex categories and the pressing need for equitable employment opportunities, education, skills training, and labour market protections, especially for women and KP groups like transgender people, sex workers and gay men and other MSM. The study emphasized the importance of fostering greater participation in support groups through enhanced community engagement efforts. However, it was noted that membership in support groups for PLHIV was more among the KP groups than the non-KPs. The study underlines the opportunity for enhanced community awareness and acceptance, emphasizing the role of supportive social networks in reducing stigma and discrimination. Disclosing one's HIV status remains a complex and challenging aspect, with participants' fears of stigmatisation in the society contributing to internalised stigma.

The evidence presented confirms that external stigma level had reduced compared to 2012, yet internalised stigma remains a concern, particularly among young people and key populations. Addressing internalised stigma necessitates efforts to change negative attitudes and ensure privacy in HIV treatment and care services. Access to treatment and care services has improved, but privacy concerns, internalised stigma and treatment interruptions persist. These findings underscore the need for comprehensive support systems to address barriers to treatment initiation and adherence.

Finally, the study highlighted gaps in participants' understanding of their rights and legal protections against HIV-related discrimination. Efforts to enhance education and awareness about these legal safeguards are crucial to ensure that individuals living with HIV are fully informed about their rights. Overall, this research offers valuable insights into the complex landscape of HIV in Zambia, emphasizing the importance of addressing stigma, improving access to care and promoting supportive communities to enhance the well-being of individuals living with HIV. It calls for a multi-faceted approach involving policy changes, education and community engagement to achieve meaningful progress in the fight against HIV-related stigma and discrimination in Zambia.

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## 6.0 RECOMMENDATIONS

It is key for the evidence collected in this study to result into concrete actions, to advocate for change to reduce stigma and discrimination experienced by people living with HIV. While some of the recommendations may be applicable to specific stakeholders depending on their mandates, most are cross-cutting and will require a collaborative effort. Based on the findings presented in this report, the study makes the following recommendations to various stakeholders:

### 6.1 NZP+, other PLHIV networks and Civil Society

- Create innovative safe spaces for individuals to share their experiences, opportunities, interactions, education and learning from one another in places such as schools, higher institutions of learning and religious institutions to promote understanding, empathy and acceptance;
- Establish and strengthen the content of counselling services to effectively address trauma and mental health concerns;
- Intensify community engagement and education campaigns to help break down barriers, improve attitudes, diminish prejudice and discrimination and challenge biases prevalent in society;
- Build resilience and empower people living with HIV to enhance self-esteem, self-acceptance, and self-worth, enabling individuals to overcome the negative impacts of self-stigma and improve their overall well-being by implementing community led and participatory interventions that consider specific needs of different populations to enhance accessibility and promote positive outcomes;
- Promote inclusivity, equality, equity and respect for all individuals, regardless of their HIV status or their association with key populations through utilisation of different media channels including television, radio and online platforms;
- Pursue policy advocacy to ensure that laws and regulations uphold principles of inclusivity and non-discrimination;
- Improve access to clear and accurate information about HIV and related services, treatment and prevention to help individuals make informed decisions about their health and access the necessary services;
- Develop a robust network of community-based organisations and healthcare providers, which should collaborate to establish support groups that offer emotional support, information sharing, and social connections among PLHIV;
- Promote innovative and sustainable community led support systems for PLHIV in their diversity to enhance benefits of support group participation and encouraging individuals to join and engage in support groups in order to enhance their overall well-being;
- Promote peer-to-peer learning and support networks to promote positive health dignity and prevention, including adherence to treatment, psychosocial well-being and accessing opportunities;
- Improve access to accurate HIV information for close associates of people living with HIV to ensure they are equipped to be a valuable resource;

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- Develop and implement rights-based education and awareness programmes to ensure that individuals living with HIV have a clear understanding of their entitlements;
  - Establish robust community platforms for dialogue and collaboration between individuals living with HIV, community organisations and healthcare providers;
  - Strengthen partnerships between civil society and government support systems that promote sustainable livelihood for the benefit of people living with HIV;
  - Strengthen reproductive health interventions for people living with HIV including young people;
  - Strengthen participation of people living with HIV in local level structures and processes to improve accountability and their well-being; and
  - Supporting the creation of a national network or support group specifically for women living with HIV.

## **6.2 KP Consortium**

- Expand the reach and inclusivity of HIV programmes for key populations, such as sex workers, people who use drugs and men who have sex with men;
- Establish and strengthen the content of counselling services to effectively address trauma and mental health concerns;
- Implement peer-to-peer programming, involving individuals from these populations to support and engage with their peers;
- Facilitate creation of safe and supportive environment by strengthening peer support networks, ensuring comprehensive and tailored services are provided to address the specific needs and challenges faced by these populations;
- Implement inclusive, gender affirming and culturally sensitive programmes;
- Collaborate with relevant stakeholders, such as government institutions, NGOs and community leaders, to drive policy changes that promote and protect the rights and dignity of PLHIV and key populations;
- Develop an advocacy strategy to amplify the message of non-discrimination articulated in Article 11 of the national constitution; and
- Collaborate with stakeholders to create an environment that upholds the principles of equality, non-discrimination and justice for all.

## **6.3 National HIV/AIDS/STI/TB Council**

- Strengthen engagement of young people in HIV interventions to improve their access to information and services that address any barriers they may face when seeking HIV-related services;
- Re-evaluate HIV promotional materials to assess content and reorient positive messaging around Positive Health Dignity and Prevention;

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- Develop Positive Health and Dignity national guidelines;
  - Foster community engagement and participation in decision-making processes related to HIV services and entitlements in the design, implementation and evaluation of HIV programmes;
  - Enhance collaborative partnerships among actors in HIV programming, to promote cross learning and foster partnerships between HIV service providers, human rights organisations, community-based organisations and legal entities;
  - Foster collaboration and partnerships between government agencies, civil society organisations, healthcare providers and community-based organisations to leverage strengths, resources and expertise to address access barriers and improve the overall HIV response;
  - Support advocacy efforts to promote and protect the rights and entitlements of people living with HIV and address HIV-related stigma and discrimination;
  - Support continuous participatory research and evaluation on the effects of interventions, searching for interventions that are making a difference across the country. The Stigma Index and other studies could also be conducted as longitudinal studies to monitor changes in internal stigma over time and assess the effectiveness of interventions and programmes.

#### **6.4 Ministry of Health**

- Provide comprehensive support and counselling services to individuals living with HIV including those who are considering disclosure of their status;
- Support interventions that address the unique needs and challenges of adolescents and young people living with HIV;
- Provide specialised counselling and support services to address the negative impact of HIV on PLHIV;
- Increase the number of certified psychosocial counsellors;
- Improve the content of counselling services to effectively address trauma and mental health concerns of people living with HIV;
- Scale up harm reduction initiatives for PWUD nationwide;
- Scale up coverage and expand treatment and prevention services by increasing the availability and accessibility of HIV treatment and prevention options;
- Ensure consistent supply of HIV prevention commodities in healthcare facilities;
- Strengthen linkages between HIV services offered in the HIV clinic and general healthcare services to ensure integrated care within health centres;
- Sensitise and train healthcare providers using person-centred approaches to ensure confidentiality and non-discriminatory practices and a safe environment where individuals feel safe and supported when seeking health care services within and outside HIV clinics;

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- Enhance treatment adherence by expanding services, addressing internalised stigma and promoting a supportive healthcare environment;
  - Collaborate with local stakeholders, including community leaders and representatives for designing and implementing contextually appropriate interventions to improve access to health services for HIV-related needs;
  - Implement strategies that address fear of being seen by others when accessing treatment by offering more discreet alternatives for treatment, such as home-based or community-based services that prioritise privacy and confidentiality while concurrently promoting awareness about the importance of consistent treatment adherence and HIV testing, as crucial for individual health and community well-being;
  - Provide clear and comprehensive information about available services, eligibility criteria and the process of accessing them;
  - Improving access to contraceptive and family planning services while addressing issues such as the denial of services and the pressure for sterilisation;
  - Promoting gender-sensitive health services and addressing issues related to stigma and discrimination; and
  - Addressing structural barriers within Zambia's health system, including material deprivation and disparities in the distribution of health facilities.

## **6.5 Ministry of Community Development and Social Services**

- Intensify programmes on financial literacy education, entrepreneurship training, microfinance initiatives, income-generating activities and financial management tailored to the specific needs and abilities of people living with HIV and KP groups; and
- Explore possibilities for expanding the coverage of existing social protection mechanisms to cover PLHIV.

## **6.6 Ministry of Justice and Zambia Law Development Commission**

- Collaborate with civil society organisations and other partners to strengthen laws and regulations that promote non-discrimination, confidentiality and equal opportunities for individuals living with HIV; and
- Improve access to legal remedies for PLHIV and KPs experiencing stigma and discrimination.

## **6.7 Ministry of Labour and Social Security**

- Develop targeted employment programmes and initiatives that specifically address the high unemployment rates among individuals living with HIV;
  - Facilitate creation of job opportunities that promote inclusive hiring practices that do not discriminate against individuals based on their HIV status. It is crucial for these initiatives to also address the gender disparities in employment, with a particular focus on supporting women and younger individuals in accessing job opportunities; and
  - Monitor implementation of HIV workplace policies.
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## **6.8 Ministry of Education**

- Improve the provision of life skills and health education in schools;
- Provide for inclusive and supportive learning environments, that is, environments that do not discriminate against individuals based on their HIV status; and
- Provide educational materials targeting stigma and discrimination in learning institutions.

## **6.9 Ministry of Youth, Sport and Arts**

- Improve and strengthen the provision of vocational trainings particularly to vulnerable population groups nation-wide; and
- Promote health and livelihood of out of school young people.

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## 7.0 ANNEX

### Annex 1: The Zambia PLHIV Stigma Index 2.0 National Steering Committee

| <i>Name</i>          | <i>Organisation</i> | <i>Role</i>       |
|----------------------|---------------------|-------------------|
| Fred Chungu          | NZP+                | Chairperson       |
| Dr Connie Osborne    | NAC                 | Vice Chairperson  |
| Kunyima L Banda      | NZP+                | Study Coordinator |
| Dr Tharcise Barihuta | UNAIDS              | Member            |
| Daphyne Williams     | PEPFAR              | Member            |
| Mrs Karen Sichinga   | CHAZ                | Member            |
| Mrs Florence Mulenga | FHI360              | Member            |
| Felix Mwanza         | TALC                | Member            |
| Hilda Shakwelele     | CHAI                | Member            |
| Dr Prisca Kasonde    | ICAP                | Member            |
| Prof Luckson Kasonka | MOH                 | Member            |
| Lenganji Nanyangwe   | SAT                 | Member            |
| Dr John Mwale        | NAC                 | Member            |

### The Zambia PLHIV Stigma Index 2.0 Technical Committee

| <i>Name</i>              | <i>Organisation</i> | <i>Role</i>            |
|--------------------------|---------------------|------------------------|
| Fred Chungu              | NZP+                | Principle Investigator |
| Kunyima L Banda          | NZP+                | Study Coordinator      |
| Dr Cleopas Gabriel Sambo | Consultant          | Consultant             |
| Estella Mbewe            | NZP+                | Member                 |
| Dennis Chibuye           | NZP+                | Member                 |
| Dr Peter K Ndemena       | NAC                 | Member                 |
| Chola Nakazwe            | ZAMSTAT             | Member                 |
| Kennedy Mutale           | Decisive Minds      | Member                 |
| Martin Silukena          | SAT                 | Member                 |
| Dr Kenneth Mwansa        | UNAIDS              | Member                 |
| Dr John Mwale            | NAC                 | Member                 |
| Dr Suwilanji Sivile      | MOH                 | Member                 |
| Dr Edgar Lungu           | UNICEF              | Member                 |
| Chilufya K Hampongo      | TALC                | Member                 |
| Fortune Chibamba         | NAC                 | Member                 |
| Kayawe Nkumbwa           | NAC                 | Member                 |

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