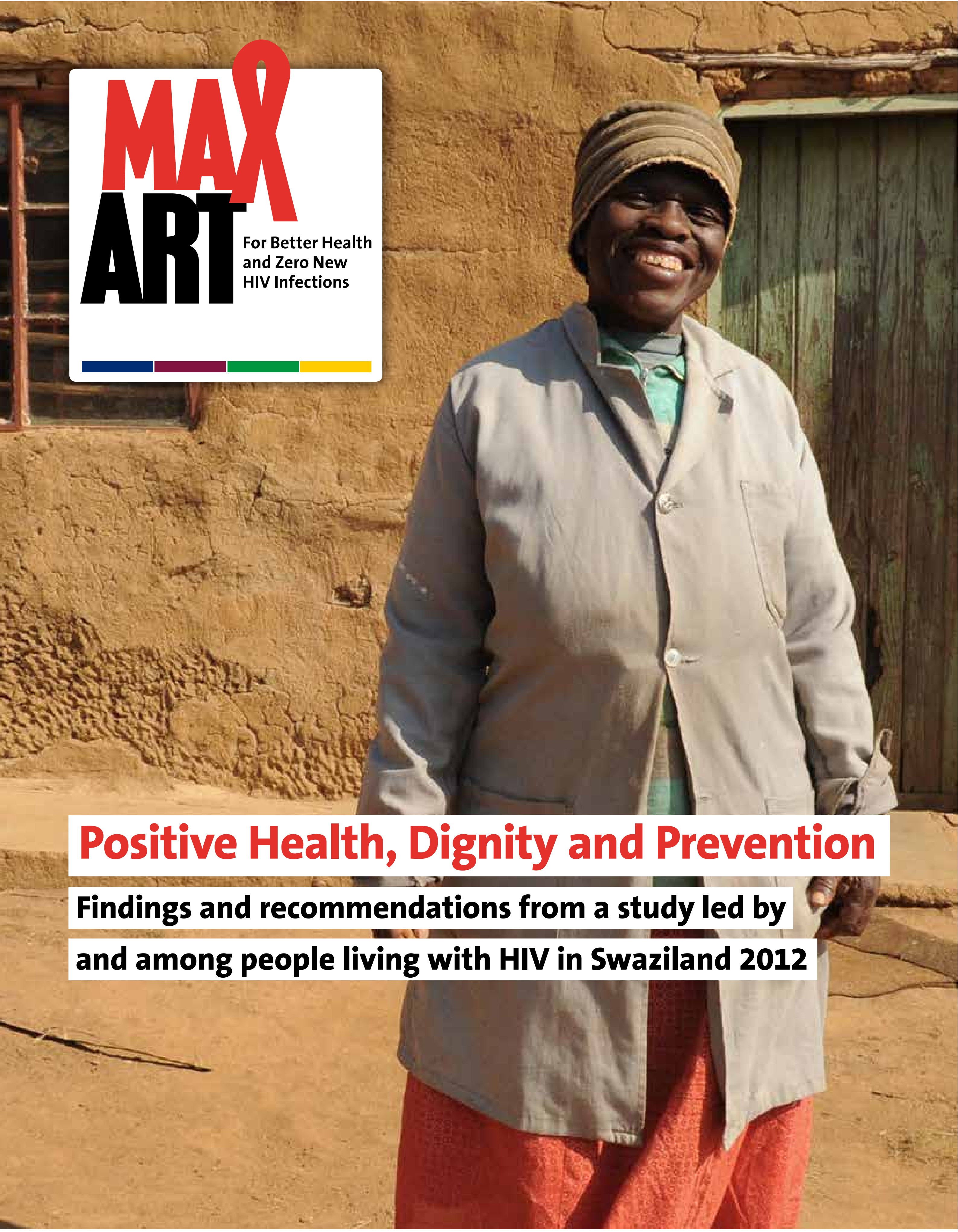

MAX ART

For Better Health
and Zero New
HIV Infections

Positive Health, Dignity and Prevention

Findings and recommendations from a study led by and among people living with HIV in Swaziland 2012

SWAZILAND NATIONAL NETWORK OF PEOPLE LIVING WITH HIV/AIDS

GNP+ GLOBAL NETWORK OF PEOPLE LIVING WITH HIV

Colophon

Positive Health, Dignity and Prevention

Findings and recommendations from a study led by and among people living with HIV in Swaziland 2012

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Design: **de Handlangers**

For more information on the *Max*ART programme visit:
www.stopaidsnow.org/treatment-prevention

SWANNEPHA

The Swaziland National Network of People Living with HIV and AIDS is a non-for-profit making local NGO founded in 2004 by people living with HIV and AIDS. SWANNEPHA aims to improve the quality of life of people living with HIV and AIDS in Swaziland through capacity strengthening of member organizations to work together with one voice to ensure a positive image of PLHIV in Swaziland. More info: **swannepha@gmail.com**

GNP+

GNP+ is the global network for and by people living with HIV. GNP+ advocates to improve the quality of life of people living with HIV and is driven by the needs of people living with HIV worldwide. GNP+ aims for equitable access to health and social services for people living with HIV by focusing on social justice, rights and involvement. More info: **www.gnpplus.net** and **infognp@gnpplus.net**

The Swaziland Ministry of Health, STOP AIDS NOW!, and the Clinton Health Access Initiative (CHAI) initiated the *Max*ART project in Swaziland. The programme partners include the Swaziland Network of People Living with HIV and AIDS (SWANNEPHA) and the Global Network of People Living with HIV (GNP+), the National Emergency Response Council on HIV/AIDS (NERCHA), national and international non-governmental organisations including the Southern Africa HIV & AIDS Information Dissemination Service (SAfAIDS), social scientists from the University of Amsterdam and researchers from the South African Centre for Epidemiological Modelling and Analysis (SACEMA).

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Special appreciation is extended to UNAIDS and ICAP for their support and valuable guidance which helped in the finalization of the Swaziland Positive Health Dignity and Prevention situational analysis Report. Also we are grateful to the technical consultants Mandhla Mehlo, Georgina Caswell and Sipho Dlamini. We are also very grateful to the Ministry of Health for their overall support and guidance.

Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal Clinic
ART	Antiretroviral Therapy
ARVs	Antiretroviral drugs
CHAI	Clinton Health Access Initiative
DHS	Demographic Health Survey
GNP+	Global Network of People Living with HIV
HIV	Human Immunodeficiency Virus
***Max*ART**	Maximizing ART for Better Health and Zero New HIV Infections
NERCHA	National Emergency Response Council on HIV and AIDS
NARTIS	Nurse-led ART Initiation Swaziland
PDA	Personal digital assistants
PLHIV	People Living with Human Immunodeficiency Virus
PHDP	Positive Health, Dignity, and Prevention
PIHTC	Provider Initiated HIV Testing and Counseling
SACEMA	South Africa Centre for Epidemiological Modeling and Analysis
SAfAIDS	Southern Africa HIV &AIDS Information Dissemination Service
SBC	Social Behavior Communication
SEC	Scientific and Ethics Committee
SIPA	Swaziland Investment Promotion Authority
SRHR	Sexual and Reproductive Health Rights
SWANNEPHA	Swaziland National Network of People Living with HIV and AIDS
TasP	Treatment as Prevention
UNAIDS	Joint United Nations Programs on HIV/AIDS

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Executive summary

At 26% Swaziland's HIV prevalence is the highest among adults in the world (UNAIDS, 2010). An estimated 210,000 people of all ages are living with HIV in Swaziland. The increasing availability of HIV treatment has enabled people living with HIV (PLHIV) to live longer, healthier lives, and to engage in issues that directly impact on their lives and those of their partners, families and communities. In 2011, the Dutch Postcode Lottery funded a proposal submitted by STOP AIDS NOW! and the *Max*ART consortium, whose primary objective was to maximize access to antiretroviral treatment (ART) in Swaziland. The scale up in access to, and uptake of, HIV testing and treatment has set the stage for an implementation study to put into practice the exciting new evidence that HIV treatment can also serve as a means of prevention. One of the components of the project was the documentation of the needs and realities of PLHIV in Swaziland, in the context of the national scale-up of access to ART. This helped to continuously improve and develop evidence informed activities.

To this end, *Max*ART partner organization Swaziland National Network of People Living with HIV and AIDS (SWANNEPHA), with support from the Global Network of People Living with HIV (GNP+), conducted a cross-sectional survey among PLHIV to document their experiences in relation to Positive Health, Dignity and Prevention (PHDP) which promotes holistic health and wellness, including human rights, legal protections, policy environment free of stigma and discrimination for PLHIV as well as access to HIV treatment, care and support services and by doing so contributes to the health and wellbeing of their partners, families and communities. A total of 919 people were reached from the four regions of Swaziland with the support of expert clients who are also people living with HIV.

This report presents the findings of the PHDP survey and it describes the experiences of PLHIV in the context of the national scale up of HIV testing, care and treatment with highlights of the important linkages between prevention, treatment, care, support and human rights. This will go a long way to inform evidence based PHDP programming. The findings of the study were analyzed in relation to the following PHDP components: empowerment, gender equality, health promotion and access, human rights, prevention of new infections, sexual and reproductive health and rights, and social and economic support.

Empowerment: Empowerment is an important concept for people living with HIV. It can be summed up as: being able to take charge of one's own life, one's health and wellbeing as well as learning to view oneself as the expert in what is involved in taking care of one's self. When people living with HIV are empowered, they are confident and vocal in expressing their needs and become active partners in managing their health.

From the findings, slightly more than half of the study participants (53%) were aware of the existence of organizations or groups that provide support services to PLHIV. The most popular organizations were the Swaziland National Network of PLHIV (SWANNEPHA) and local, community level support groups. Affiliation to a society or organization that provides services to PLHIV was fairly high, just over half of the participants reported that they were affiliated with key PLHIV bodies in the form of civil society and support groups. However, involvement in the development processes for laws and policies that affect PLHIV was low, with only 21% of respondents having participated in policy and/or law formulation. Such involvement was however meaningful, taking the form of consultation, development of a draft statute or law and participating in the validation process of a policy. In addition to formal groups and organizations, PLHIV provide support to peers, with just over half of the study participants reporting that they had provided support to other PLHIV. Peer support took the form of emotional and psychosocial support, information sharing and referrals to other services.

Gender equality: There were no differences between the perceptions of males and females regarding gender equality. However, there was a general view that PLHIV were more likely to experience gender-based abuse and violence compared to people who are HIV negative. Overall, most of the real-life experiences of males and females living with HIV with regards to gender based abuse and violence, were similar. The only significant differences in the experiences of males and females living with HIV were evident in the following areas:

- More males than females were denied sex by sexual partners;
- More females than males were denied financial support by sexual partners;
- More females than males were denied the right to negotiate the use of a condom.

It must be stressed that although respondents scored their perceptions of gender based violence highly, averaging 49% (range: 36% to 57%) on the 12 gender-based abuse and violence questions, their actual experiences of gender-based abuse and violence were much lower, averaging 9% (range 1% to 18%).

Health promotion and access: The majority of respondents did not test for HIV regularly before they were diagnosed HIV positive. By far the most common reason given for receiving the test that turned out to be positive for HIV infection was weight loss/falling sick. Of the 652 (71%) respondents who were on ART at the time of the study, almost half started ART soon after being diagnosed HIV positive, and most started ART to stay healthy and alleviate symptoms, while 8% initiated ART to prevent mother-to-child transmission of HIV. Most of the respondents, 64% had a treatment supporter, although about a fifth of respondents reported that their treatment supporters did not provide the necessary support.

There were some worrying findings concerning ART. Almost half of the respondents who were on ART felt that ART follow-up care should only be when they fall sick, not routine and 10% of the respondents who were not on ART, had been on ART and stopped treatment. In addition, 35% of respondents who were neither on pre-ART nor ART reported that they did not have time to attend follow up care, while 46% were either not offered pre-ART or were unaware of pre-ART services. About a third of respondents on ART thought that it was difficult for people to take ARVs because of stigma anddiscrimination, lack of food, lack of family support, side effects, tiredness of taking ARVs, distance to health facilities, costs and periodic stock-outs of ARVs.

Human rights: Half of the respondents did not consider themselves to belong to the most at risk population (MARP) group, while the most common MARPs identified by the remaining half were those orphaned at a young age and those being a migrant. The study revealed high levels of disclosure of HIV status to sexual partners and members of the immediate family, with most of the respondents personally revealing their HIV status or asking someone else to disclose status on their behalf. The main reason for disclosing one's HIV status was that respondents thought they would get support if they disclosed their status.

Most of the respondents (84%) had not experienced any discrimination because of their HIV status in the 12 months preceding the study. Of those who had experienced discrimination in the 12 months preceding the study (n=127), the majority felt they were discriminated against at social gatherings or they were rejected by family members and by sexual partners. The majority of respondents who felt they were victims of discrimination (40%) did not take any action in response to the discrimination. Reasons for not taking any action in response to the discrimination included not knowing where to go (47%), being afraid (28%, not knowing what to do (26%) or they did not think it would make any difference (18%).

Almost 90% of respondents did not know of any laws in Swaziland that could protect them from discrimination and stigma as PLHIV and only 24% of respondents reported having access to free legal services. However, almost three quarters of the responds were able to identify SWANNEPHA, non-governmental organizations, the police, women's organizations and the National AIDS Program as organizations/institutions that can help them deal with stigma and discrimination. In addition, most respondents were aware of the rights they have as PLHIV, including the rights to: health, work, marry and have a family, privacy and education.

Prevention of new infections: Most of the respondents (49%) felt that both partners in a sexual relationship were equally responsible for preventing HIV infection, while 38% felt that each person is responsible for their own protection and 9% thought that they, as PLHIV, were fully responsible for preventing HIV transmission to their sexual partners. Reported condom use was high, with 79% of respondents reporting using condoms most of time when engaging in sexual activity, and an even higher proportion (of all participants), 91%, reporting using a condom at the last sexual encounter. A worrying finding was that about 15% of respondents had acquired a sexually transmitted infection since being diagnosed HIV positive.

The use of illegal drugs/substances was low, with only 11% of respondents reporting having used cocaine, marijuana, heroin or any other drugs in the 12 months that preceded the study. Alcohol use was similarly low, with only 14% of respondents reporting drinking alcohol in a given week.

> About 68% of respondents knew that the likelihood of HIV transmission is reduced to nearly zero when an individual adheres to ART treatment, has a low viral load for at least 6 months, and has no STIs.

Sexual and reproductive health and rights: Knowledge of the sexual and reproductive rights of PLHIV was high, with most respondents reporting that they were aware of their rights to have sex, get married and to have children. Only a single respondent reported that they had been told to terminate a pregnancy by a health care worker, and all of the respondents reported having received messages about the management of their sexual lives from health care workers. Knowledge on the use of contraceptives was high, with male condoms, female condoms, contraceptive pills, abstinence and injectable being the most used contraceptives.

Almost half of the female respondents, who participated in the study, reported having given birth since their HIV diagnosis. The numbers of women whose last pregnancy was intended or planned compared to those whose last pregnancy was unintended or unplanned were not significantly different. Of the 640 women who had given birth since their HIV diagnosis, 66% were assisted by a healthcare professional during the delivery of their last child.

A worrying finding was that 77% of the women who had given birth since being diagnosed HIV positive reported not having received counselling from a health professional on exclusive breastfeeding (which was the WHO recommendation at the time of the study), and only 6.6% women reported having been counselled by a health professional on ARV prophylaxis for their new-born. More than half of the women indicated not having received counselling on HIV testing for the infant.

Effectiveness of PLHIV groups and networks and social and economic support: When asked "What type of services and/or activities does the organisation (the support organisation they attend) carry out?" slightly more than half of the respondents (52.4%) indicated that their organization provides emotional/psychological support, 37.1% said that it provides information on health, 23.6% said it provides spiritual/moral support, HIV prevention support, physical care and referrals to other services. Less common were: economic support, capacity building and empowerment

When asked to rate how important they feel it is to belong to a network of people living with HIV, 569 participants thought it was very important, 172 thought it was important while 20 participants thought it was not important.

Recommendations

The key recommendations include a call to government, PLHIV networks and other stakeholders to capacitate PLHIV to understand basic human rights and legal remedies available to them. Additionally, that government should promote and implement strategies to ensure basic human rights are protected. Governmental and civil society organizations that work on HIV should use a right-based approach in designing, implementation and evaluating their programs and projects. PLHIV service providers and networks should be strengthened to continually devise strategies to remain relevant and responsive to the changing needs of their constituencies. Service providers should strengthen/improve the meaningful, coordinated and collective participation of PLHIV in the formulation of evidence-informed policies, strategies, and services.

1. Background

1.1. HIV/AIDS in Swaziland

According to the 2007 population census, Swaziland has a population of 1,218,449 with the majority of the population residing in rural areas. The population is distributed across four regions, as follows: Hhohho (28%), Manzini (31%), Shiselweni (21%), and Lubombo (20%).[1] The median age is estimated to be 19.9 years for men and 20.7 years for women, highlighting the young population structure in Swaziland.[2]

HIV prevalence in Swaziland is among the highest in sub-Saharan Africa, and has increased substantially over the years. Data from women attending antenatal clinics (ANC) measured HIV prevalence from approximately 3.9% in 1992 to 42% in 2008.[3] To supplement sentinel surveillance data, and to provide more accurate national-level HIV prevalence estimation, the Demographic and Health Survey 2006/7 (DHS) incorporated HIV testing in 2007 and measured an overall HIV prevalence of 26% among the 15-49 age group.[4]

Women are disproportionately affected by the HIV/AIDS epidemic in Swaziland. According to the Swaziland National Emergency Response Council on HIV and AIDS (NERCHA) and the Joint United Nations Programme on HIV/AIDS (UNAIDS), in 2011 an estimated 105,900 women age 15 and older live with HIV, compared to approximately 76,892 men.[5] Unequal power relations and gender discriminations disadvantaging women are key factors underlying the higher prevalence of HIV in women in Swaziland. The drivers of the epidemic in Swaziland have been identified as multiple concurrent partnerships, intergenerational sex, low condom use, low HIV testing and disclosure levels, and high prevalence of sexually transmitted infections.[6]

1.2. PLHIV and the Positive Health, Dignity and Prevention Framework

The increasing availability of HIV treatment has enabled PLHIV to live longer and healthier lives and to engage in the issues that directly impact on their lives and those of their communities. According to statistics from the Swaziland Ministry of Health 2013, approximately 98,747 out of 101,104 PLHIV in need of treatment in Swaziland are on ART.[7]

In the past, understanding of HIV prevention as it relates to PLHIV has been inconsistent or ill-defined. Policies and programmes targeting PLHIV were designed, for the most part, without the involvement of PLHIV at the beginning of the pandemic.

In response to this concern, a technical consultation was organised by the Global Network of PLHIV (GNP+) and UNAIDS in April 2009 in Tunisia. At this meeting, the term ‘Positive Health, Dignity and Prevention’ (PHDP), was agreed upon to refer to the linking of HIV treatment, prevention, support and care issues within a human rights framework.[8] PLHIV worked with civil society, government agencies, international development agencies, UNAIDS, cosponsors and donor agencies to identify the components of Positive Health, Dignity and Prevention and to develop values and principles underpinning it.

> Positive Health, Dignity and Prevention highlight the importance of placing the person living with HIV at the centre of managing their health and wellbeing.

It introduces a shift from the more limited concept of ‘positive prevention’ that focuses only on people living with HIV preventing the transmission of HIV to emphasizing the importance of addressing prevention and treatment simultaneously and holistically. This is a distinct shift from narrowly targeting changing the behaviour of people who know that they are HIV-positive, with limited consideration of how failure to meet their needs for social support, human rights and treatment of PLHIV can undermine HIV treatment and prevention efforts. A Positive Health Dignity and Prevention approach involves recognizing the value of PLHIV as partners, leaders and implementers of the HIV response, including HIV prevention. Further, it promotes holistic health and wellness, including human rights, legal protections, policy environment free of stigma and discrimination for

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[1] NERCHA and UNAIDS. Swaziland HIV estimates and projections report. July 2010.

[2] CIA World Fact book, 2011 estimates

[3] Swaziland Ministry of Health sentinel surveillance report 2010

[4] Swaziland Demographic and Health Survey, 2007.

[5] NERCHA and UNAIDS. Swaziland HIV estimates and projections report. July 2010.

[6] NSF 2009 -2014 <National Strategic Framwork on HIV and AIDS

[7] Swaziland Ministry of Health, Monitoring and Evaluation Unit. Monthly statistics (spreadsheet), September 2013.

[8] GNP+ and UNAIDS. Positive health, dignity and prevention: a policy framework. Global Network of People Living with HIV/AIDS: Amsterdam. January 2011.

PLHIV as well as access to HIV treatment, care and support services and by doing so contributes to the health and wellbeing of their partners, families and communities. PHDP programmes and efforts must additionally be responsive to the needs of key affected populations.

Positive Health, Dignity and Prevention is guided by the following values and principles:

- People living with HIV must be leaders in the design, programming, implementation, research, monitoring and evaluation of all programs and policies affecting them.
- A human rights approach is the foundation of Positive Health, Dignity and Prevention.
- Preventing HIV transmission is a shared responsibility of all individuals irrespective of HIV status.
- Sexual and reproductive health and rights must be recognized and exercised by everyone regardless of HIV status.

The objectives of Positive Health, Dignity and Prevention are:

- To ensure that undiagnosed and diagnosed people, along with their partners and communities, are included in HIV prevention programs that highlight shared responsibilities regardless of known or perceived HIV status and have opportunities for empowerment;
- To invest in community development, networking, capacity-building, and resources for people living with HIV organizations and networks towards scaling up and supporting social capital programs and in-depth understanding of human rights and the law.

Positive Health, Dignity and Prevention can be achieved through the following strategies:

- Providing a supportive and protective legal and policy environment that aims to reduce and eventually free people from HIV-related stigma and discrimination.
- Improving and maintaining the health and well-being of people living with HIV, which, in turn, will contribute to the health and well-being of their partners, families and communities.
- Promoting holistic health and wellness, including universal, equitable access to innovative HIV Testing and Counselling, care and support as well as timely access to treatment and monitoring.
- Addressing factors that undermine health and dignity which may include: poverty and food insecurity; lack of mental and psychosocial support; lack of educational opportunity; social exclusion; gender inequality; and stigma and discrimination based on HIV-positive status, behaviours such as injecting drug use, sex work and/or sex between men, and identities such as being lesbian, gay, bisexual, transgender or intersex.

1.3. SWANNEPHA

The Swaziland National Network of People Living with HIV and AIDS (SWANNEPHA) was founded in 2004 by the Swaziland Ministry of Health in collaboration with NERCHA, UNAIDS and Action Aid after a situational analysis for PLHIV which showed poor coordination among the forty six associations that existed at the time. This network was formed to ensure efficacy of programme delivery among PLHIV. SWANNEPHA's mission is to enhance an enabling environment that empowers PLHIV with survival skills and their rights for an improved quality of life.

Maximizing ART for better health and zero New HIV infection (*Max*ART) Project in Swaziland

*Max*ART: Maximizing ART for Better Health Prevention and Zero New HIV Infections, an initiative of Swaziland's Ministry of Health (MOH), is a unique package of interventions aimed at addressing the remaining barriers to HIV testing, care and treatment and further strengthening the collective efforts of the many involved programmes and partners in the country. Through funding from the Dutch Postcode Lottery's Dream Fund the project supports a number of interventions and systems strengthening activities aimed to improve the health of the people of Swaziland through dramatically scaling-up HIV testing, improving access to ART so that 90% of those in need at the current eligibility requirements are on treatment, and reducing loss-to-follow-up of clients on treatment.

This scale up in access to, and uptake of, HIV testing and treatment will set the stage for an implementation study to put into practice the exciting new evidence that early treatment has not only individual health benefits, but also contributes to the prevention of HIV transmission (often referred to as Treatment as Prevention). The study aims to assess the feasibility, acceptability, clinical outcomes, affordability, and scalability of offering ART to all HIV-positive individuals in Swaziland's government-managed health system. Enabling people living with HIV to access treatment immediately after they test HIV-positive may prove a game-changing method for ending new HIV infections.

One of the critical monitoring and evaluation components of the project is to document *the needs and realities of PLHIV in Swaziland,* in the context of the national scale-up of access to antiretroviral treatment, and Treatment as Prevention (TasP). To this effect, *Max*ART partner organization SWANNEPHA with support from GNP+ conducted a cross-sectional survey among PLHIV to document their experiences in relation to PHDP.

2. Study overview

2.1. Problem and rationale

The purpose of the study was to document the experiences of PLHIV in relation to the components of PHDP to inform programming. These include:

1. Empowerment,
2. Gender equality,
3. Health promotion and access,
4. Human rights,
5. Prevention of new infections,
6. Sexual and reproductive health and rights, and
7. Social and economic support.

2.2. Objectives

Specific objectives of the study are as follows:

1. To document the experiences and needs of PLHIV, and understand the barriers and opportunities they face with regards to PHDP;
2. To inform SWANNEPHA, the *Max*ART program, and other stakeholders about the needs and realities of PLHIV on the ground;
3. To measure changes and impact of indicators related to the PHDP components described above.

2.3. Methodology

Study design

A cross sectional survey of a country-wide representative sample of PLHIV was conducted in December 2012. PLHIV were at the centre of this study as interviewers and interviewees. PHDP studies are preferably done by PLHIV as stipulated in the PHDP framework; this study followed the same standard. Interviewers were selected from the four regions of the country via the SWANNEPHA secretariat office in Mbabane, as well as through the two regional offices in Lubombo and Shiselweni.

Interviews were conducted through support groups first, before beginning recruitment at ART facilities. Upon recruitment at either the support groups or ART facilities, PLHIV were asked if they were a member of a support group, or had already participated in the survey as it was likely that some clients recruited at ART facilities were members of support groups. If they had participated, they were not interviewed again, and another recruit was sampled for replacement. A careful record was maintained of previously-interviewed support group members who were sampled in the ART facility recruitment.

Ethical considerations

The following ethical considerations were observed to ensure that basic human rights of individuals were not violated in the course of the study.

a. **Ethical clearance:** Ethical clearance was obtained from the Scientific and Ethics Committee (SEC) of the Ministry of Health to conduct the study.
b. **Informed consent:** Written consent was obtained from participants in the PHDP study. The consent was obtained before interviews took place and was preceded by an explanation of the study and its purposes. Participants who were not willing to participate were not coerced or forced.
c. **Privacy and Confidentiality:** Privacy was ensured during interviews by ensuring that participants were interviewed where they were not overheard, as agreed with support groups and their participants. No personal identifying information was collected. To secure confidentiality the index questionnaires and informed consent forms were identified by a unique identifying code (as opposed to the name of the interviewee). Each code included a country code of two digits; a region code of two digits; an interviewer code of two digits; an interviewee code of two digits; and the location where the interview occurred. e.g. SD-HH-HM-VV.

   Data collected was kept safe where no one had access other than the SWANNEPHA Team. Training of research assistants emphasized the importance of privacy and confidentiality. Reporting ensures that findings cannot be linked to individuals.

Population sample

The study population was PLHIV in Swaziland across the four regions. Sample size was calculated using an assumed 45% baseline measurement compared to a 55% follow-up measurement. Assuming a 20% refusal rate for the study and a design effect of 2, a sample of 978 participants was required. With 978 people recruited, the estimated confidence interval for the most conservative 50% indicator estimate provided for a minimum ±5% degree of accuracy from the true population proportion, or a confidence interval of 45% to 55%.[9]

A two stage sampling procedure was used. In the first stage of sampling, Support Groups and Health Facilities were randomly selected from the SWANNEPHA database, which served as a sampling frame. The breakdown of the first stage sample was 50% from support groups and 50% from health facilities, and these groups/facilities were selected based on regional and sub-regional location, urban and rural location, membership size, and sex of members.

In the second stage of sampling, study participants from support groups were randomly selected while any participant in the selected health facilities who met the selection criteria was enrolled until the desired sample size was met.

The following criteria were used:

- 50% from support groups; 50% through expert clients at health facilities
- 40% on ART; 60% PLHIV pre-ART
- 25% from each of the four regions in Swaziland
- 40% from urban areas; 60% from rural areas
- 40% male; 60% female

The basic eligibility criteria for participants were as follows:

- Any person living with HIV
- Had been diagnosed with HIV for a minimum of 6 months
- 18 years of age or older
- Provided informed consent to participate
- Was a member of the Support Group selected for participation or have come to the selected facility

Participants who were unable to give informed consent because of alcohol intake, other substance misuse, mental incapacity or were too ill to participate were excluded.

Data collection

A tool developed by GNP+ and SWANNEPHA—previously utilized effectively in Tanzania, Bolivia, and Vietnam—was adapted and used for data collection (Annex 1). The questionnaires were translated into SiSwati to enable interviews with participants who are not conversant with English language. Ten research assistants were recruited among PLHIV and trained for three and half days in the required procedures and tools that were used to collect data. The research assistants were supervised in the field by four regional supervisors who checked for completeness of tools and collected them. Researchers used personal digital assistants (PDAs), to collect data from respondents.

Before the commencement of data collection, data collectors were trained on the data collection tool and the questionnaire was pre-tested. This process enabled the study team to agree on content and flow of questions, management of interviews, data entry and recording.

Data management and analysis

The study used Perseus Survey Solutions 7 in the PDAs to display the questionnaire, receive responses, back-up the data, and download the latter into an MS Access database. Data were analysed using STATA (version 12). Descriptive statistics, frequencies and percentages, were calculated for the demographic variables as well as the different thematic areas. Cross tables were populated as and when necessary.

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[9] Given the unavailability of standard errors, a binomial exact 95% confidence interval was used to generate the estimate for a 50% proportion, and was calculated in Stata using the CII command.

3. Findings

3.1. Description of Respondents

A cross-sectional survey was conducted among 919 out of a sample size of 978 PLHIV. For two participants, age was missing and they were excluded. Participants were approached through 100 support groups (49%), and through expert clients in 22 health facilities (51%). Respondents included men (30%) and women (70%), as shown in **table 1.** Also the Table shows that 24.7% of the respondents were 50 years and above with 92% from rural areas and 8% from urban. Thirty percent of the respondents were from Lubombo, 27% Shiselweni, 24% Manzini and 19% Hhohho. Forty seven percent (47 %) of the respondents were married, 27% were single and never married, 14% Widowed, 8% co-habiting and 4% divorced.

3.2. Empowerment

The empowerment of PLHIV remains at the core of PHDP. To determine empowerment the study focused on issues of affiliation, involvement in law and policy formulations and reviews, awareness about available support systems and use of peer support structures.

Society affiliation

The study participants were asked if they belong to any civil society/support group/association as a person living with HIV and 53% indicated that they were affiliated as shown in **table 2.** This may mean that about half of the PLHIV population have opportunities for linkages to support structures and networking.

When those affiliated were asked of activities they have been involved in, the majority (45.5%) said they were involved in meetings, 32.2% in support group activities and 27% in training areas whilst a minority (3.9%) were involved in advocacy and national forums (2.8%) as shown in **figure 1.**

Table 2: Civil society/support group/association affiliation of PLHIV

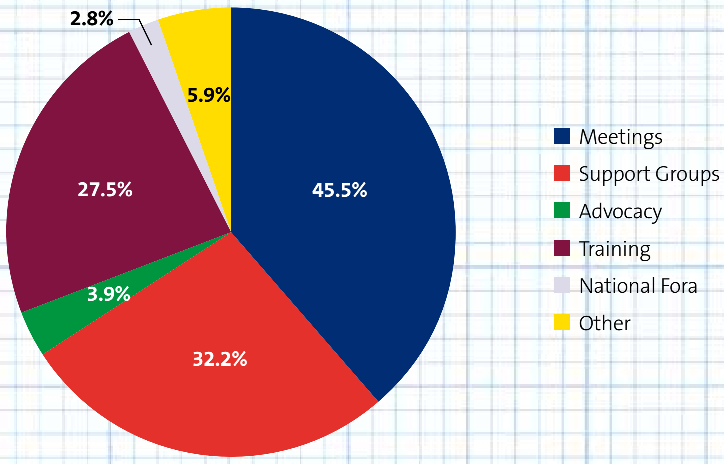
	Total number	Percentage
Yes	489	53.2%
No	426	46.4%
Missing	4	0.4%

Table 1: Age and sex of study participants

Age	Women		Men		Total Number	Percentage
	Number	Percentage	Number	Percentage		
18-19	5	0.8	2	0.7	7	0.8
20-24	42	6.6	11	3.9	53	5.8
25-29	82	12.8	23	8.2	105	11.4
30-34	84	13.1	40	14.3	124	13.5
35-39	108	16.9	45	16.1	153	16.6
40-44	101	15.8	37	13.3	138	15.0
45-49	76	11.9	36	12.9	112	12.2
50+	142	22.2	85	30.5	227	24.7
Total	**640**	**100**	**279**	**100**	**919**	**100**

Figure 1: Activities PLHIV were involved in through civil society/support group/association (n=489)

Note: Multiple responses were possible



Law and Policy involvement

When respondents were asked how they have been involved in development of laws and policies that affect people living with HIV since their diagnosis, 79% said they have never been involved in development processes for laws and policies that affect PLHIV. Of the 21% that were involved; 59% participated in consultation, 16% participated in development of a law, 17% were informed that the law was being developed and 9% formed part of the validation process.

Society awareness

When respondents were asked if they knew any organizations or groups that provide support services to people living with HIV; 53.2% said they did, and the most known organizations were the network of PLHIV (80.9%) and support groups (78.2%) as shown in **table 3.**

Table 3: Organizations known by PLHIV (n=481)

Note: Multiple responses were possible

Organization known	Number	%
PLHIV support group	376	78.2%
Network of PLHIV	389	80.9%
Non-government organization	230	47.8%
Faith-based organization	121	25.2%
A human rights organization	39	8.1%
Departmental or national AIDS committee or council	60	12.5%
International non-governmental organization	14	2.9%
UN organization	90	18.7%
Other	8	1.7%

Peer support

Table 4 shows a list of the type of support that has been provided by PLHIV in which 52% of respondents said they have provided some form of support to other PLHIV in the last 12 months, and the majority (26.7%) provided emotional/psychosocial support whilst 11.4% shared information, (11.3%) provided HIV prevention support and 10.6% referrals to other services. To note, very few PLHIV received legal support (0.2%).

Table 4: Types of peer support provided (n=429)

Note: Multiple responses were possible

Type of support	Number	%
Emotional/ Psychological Support	308	26.7%
Economic Support	106	9.2%
Referral to other services	122	10.6%
Health care support	114	9.9%
Companionship	50	4.3%
Physical care	56	4.8%
Information support	132	11.4%
Spiritual / moral support	102	8.8%
Legal support	2	0.2%
HIV prevention support	130	11.3%
Capacity building	28	2.4%
Other	5	0.4%

3.3. Gender Equality

Gender inequity is recognized as a major barrier to effective care, treatment, and prevention efforts. As HIV and AIDS programs are rolled out and scaled up, gender inequity can adversely affect access, utilization as well as adherence especially to treatment in different ways for HIV-positive women and HIV-positive men. For example, factors affecting HIV-positive women's ability to access antiretroviral drugs, include financial and time costs of traveling to service points, lack of confidentiality, and the need to seek permission from partners to access services.

To determine issues of gender equality, the study focused *on perceptions towards* situations more likely to be experienced by HIV positive people in comparison to HIV negative people, real *experiences* of PLHIV since diagnosis and actions taken in response to the experiences.

Table 5: Perceptions towards situations more likely to be experienced by HIV+ people in comparison to HIV- people

	Male	Female
Physically abused by a sexual partner?	35%	36%
Denied financial support by a sexual partner?	57%	56%
Deliberately ignored (not talked to) by a sexual partner?	53%	53%
Denied sex by a sexual partner?	56%	53%
Denied the right to negotiate non-penetrative sex ?	43%	42%
Denied the right to negotiate a contraceptive method?	49%	47%
Psychologically abused by a sexual partner (shouted at, insulted, despised, blamed)?	58%	57%
Denied the right to negotiate the use of condoms?	50%	48%
Forced to have sex against your will?	33%	39%
Forced to be separated from your family (i.e., you cannot call or visit them)?	45%	44%
Being threatened by a partner?	54%	53%

Perceptions

The study participants were asked their opinion if people living with HIV are likely to experience gender ills compared to HIV negative people. **Table 5** shows that there are differences between the perceptions of males and females with regards to whether people living with HIV are more likely to experience the enlisted gender ills more than HIV-negative people. However, there is a general view amongst the respondents that PLHIV are likely to experience gender related ills compared to those who are HIV negative and the perceived most likely to happen is psychological abuse by a sexual partner (58%), being abandoned (57%) and denied sex (56%) by sexual partner.

Experiences

Participants were asked if they have personally experienced any discriminatory situations (as indicated in **table 6**); most of them said they had experienced the following situations:

- Denied sex by sexual partner (29.4% males and 22.8% females)
- Denied financial support by a sexual partner (11.8% males and 28.6% females)
- Deliberately ignored by partner (22.9% males and 21.6% females)
- Psychologically (emotionally) abused by a sexual partner (20.1% males and 19.2% females)
- Being threatened by a partner (12.5% males and 15.8% females)

Comparing experiences of males and females, the study shows that there is difference in the actual experiences of males and females living with HIV regarding being denied financial support by a sexual partner (11.8% males and 28.6% females), being denied the right to negotiate the use of a condom (with 6% in males and 13% in females) and being denied sex by sexual partner (29.4% males and 22.8% females) with more men being denied sex and more females being denied financial support as well as the right to negotiate the use of a condom. On the list of the experiences is being forced to terminate pregnancy (2% females), forced to separate from family (4% males, 6% females) and being denied the right to negotiate non penetrative sex (6% males, 5% females). To note is that many of the situations affect males and females almost in the same way. Only a few situations as said earlier affect males differently than females.

Table 6: Gender Based Violence Experiences since diagnosis for HIV positive people by gender

	Male	Female
Denied financial support by a sexual partner?	12%	29%
Deliberately ignored (not talked to) by a sexual partner?	23%	22%
Denied sex by a sexual partner?	29%	23%
Denied the right to negotiate non-penetrative sex ?	6%	5%
Denied the right to negotiate a contraceptive method?	3%	7%
Psychologically abused by a sexual partner (shouted at, insulted, despised, blamed)?	20%	19%
Denied the right to negotiate the use of condoms?	6%	13%
Forced to have sex against your will?	6%	9%
Foreced to terminate your pregnancy	1%	2%
Forced to be separated from your family (i.e., you cannot call or visit them)?	4%	6%
Being threatened by a partner?	13%	16%

Actions taken to address Gender Based Violence

> Having experienced gender based abuse; the study (figure 4) shows that 56% of males and 49% of females did nothing in addressing these issues, whilst 26% of males and females sought help.

No civil society assistance was sought by males, and only 3% of females sought assistance from civil society. This is a thought-provoking finding because one would expect more people to seek assistance from civil society organisations as it is believed that they operate mostly in communities. In addition it is worth noting that very few people sought legal assistance (2% males, 4% females) and religious assistance (5% males, 8% females) in a country that is believed to be highly religious. In **figure 2** the results also show that PLHIV are less assertive as few respondents confronted the perpetrators (5% males, 4% females) or tried to sensitize those involved (6% males, 6% females) protection services. Only 3% males and 2% females reported to have used comprehensive legal services.

Utilization of support services by gender

Regarding utilisation of available services, following the experiences of the situations mentioned above, the findings **(figure 3)** indicate that most of the respondents did not utilise support services (67% of males and 69% of females). Of those who utilised services, 19% of males and 23% of females utilised psychological services in care and treatment centres, 11% of males and 6% of females utilised family structures for support.

Figure 2: Actions taken to respond to gender based abuse

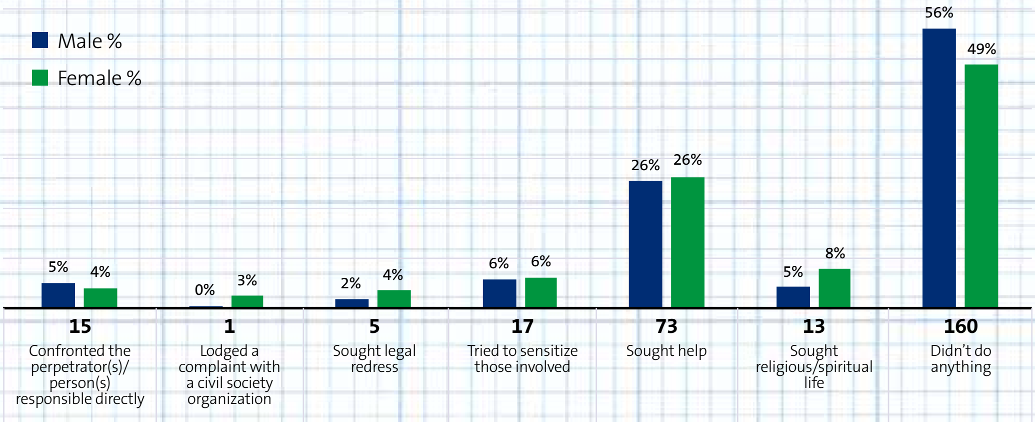
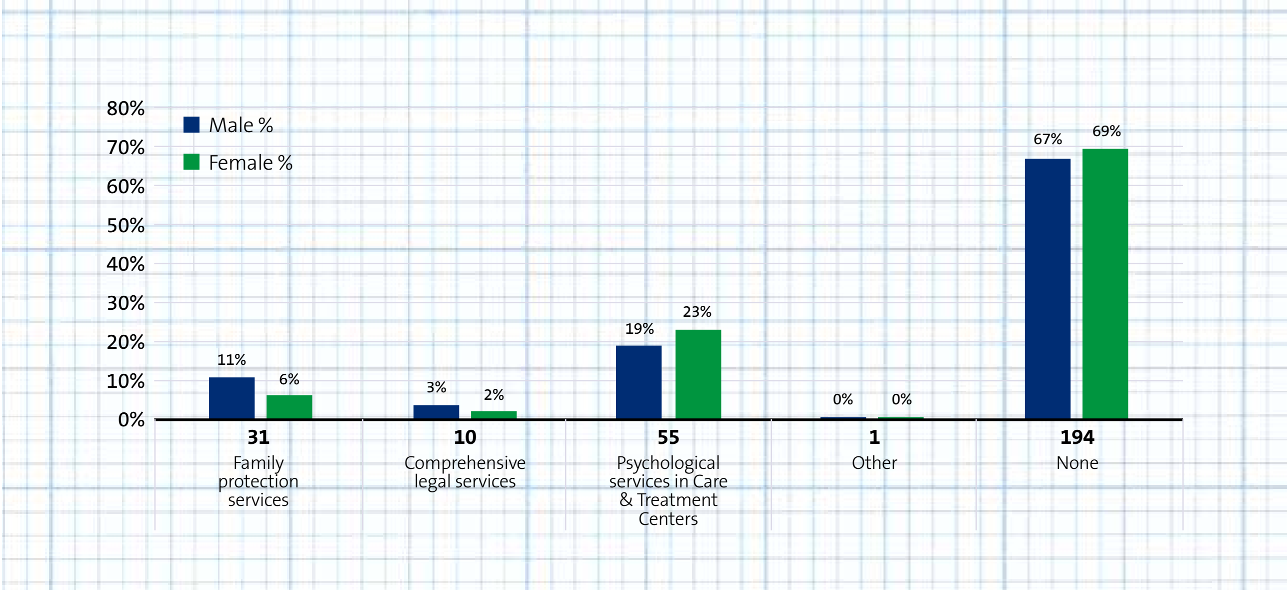


Figure 3: Support services utilization by PLHIV



3.4. Health promotion and access

Health promotion and access to care as well as the ability of existing public health systems to provide essential services to PLHIV is critical in ensuring long and sustained lives and is central to helping individuals prevent and avoid unfavorable health outcomes and medical costs. In order to be appropriate in the provision of these essential services; groups that face barriers to accessing health services needs to be identified and their personal health needs addressed and linkages to applicable health services assured through developing and implementing interventions that address the barriers they face in attempting to access the services as well as assessing access to and availability of state health services.

To assess health promotion and access for PLHIV in Swaziland, the study examined the quality of care, determined through frequency and reasons for testing, CD4 count access, time intervals required by nurse/doctor to attend follow-up ART care and the ART experience; explained through gauging the time interval for starting treatment after diagnosis and reasons for difficulty in taking ARVs.

Quality of Care

When participants were asked how often they had tested before diagnosis, 81.1% said they had not tested regularly before the positive diagnosis with HIV. When they tested, 38.6% of the respondents tested through Provider Initiated HIV Testing and Counselling while 61.4% tested through Client Initiated HIV Testing and Counselling. **Table 7** shows that when prompted of the reason for testing, most respondents sighted weight loss/falling sick (42.6 %) followed by Hospitalisation (12.7%), doctors' advice (11.7%) and partners' risky behaviour (10.1%). Least were military enrolment screening and insurance requirement both at (0.1%). Of those that had tested for HIV, when asked if they received pre and post-test counselling, the majority (96.4%) said they received both Pre-test and post-test counselling

Table 7: Reason for last test (n=919)

Note: Multiple responses were possible

Reason	Number	%
Doctors' advice	129	11.7%
During hospitalization	140	12.7%
Partner's risky behavior	112	10.1%
Own risky behavior	96	8.7%
Falling sick/losing weight	470	42.6%
Spouse/partner positive	45	4.1%
Child positive	22	2.0%
Requirement of Male Circumcision	5	0.5%
Insurance requirement	1	0.1%
Employment requirement	10	0.9%
Visa requirement	0	0.0%
Antenatal clinic requirement	44	4.0%
Partner's illness	14	1.3%
Death of partner	9	0.8%
Pre-marital testing	6	0.5%
Military enrollment screening	1	0.1%

and only 1.2% received only pre-counselling, 0.9% received only post-test counselling and 1.5% received no counselling at all.

HIV Care

Table 8 shows that while in HIV care, 96% of respondents had a CD4 count test and 94.5% received results. 14% of these were not on ART yet their CD4 was less than 350 (it is worth-noting that this may be due to the some clients being diagnosed when the eligibility criteria was still CD4 count <350c/ml).

Table 8: Last 6 months CD4 assessment (N= 919)

CD4 assessment	Number	%
CD4 taken	882	96%
Received CD4 results	868	94%
With CD4 less than <350	265	30%
Not on ART out of <350 group	38	14%

Most participants (44.5%) were required by a nurse/doctor to make follow up care visits every 2 months, 35.1% every month and 18.6% every 3 months **(table 9).** On the contrary, when asked how often they thought it necessary to attend follow-up ART care; 47.9% of respondents on ART felt that follow up care should only be when they fell sick, 18% felt it should be every 2 months, 14.6% said every 3 months and 12.1% said every month.

Table 9: How often are you required by nurse/doctor to attend follow-up ART care?

Frequency of visits	Number	%
Every two weeks	7	1.1%
Every month	229	35.1%
Every 2 months	290	44.5%
Every 3 months	121	18.6%
Every 6 months	3	0.5%
Missing	2	0.3%

During health facility follow up ART care, 44.2% of respondents said they spent 1-2 hrs, 29.6% spent less than an hour, and 16.1% spent 2-4hrs, while 10% spent more than 4 hours in the health facility. When the participants were asked which health providers they normally see (for refills and clinical follow-up); 95.7% said they were attended by nurses, 42.8% by doctors and 38.7% by Expert Clients (Note: Multiple responses were possible). Given that a high number of clients interact with nurses, further scale up of nurse led ART initiation could reach more PLHIV.

ART Perception

Of the 652 (70.9%) respondents currently on ART, 48.5% started treatment immediately after diagnosis. When asked about the time taken for them to take ART after diagnosis, the majority started at least within the first year, 12.9% within three months and 15.5% three months to a year **(table 10).**

Table 10: How long after diagnosis did you start treatment? (n=653)

Note: Multiple responses were possible

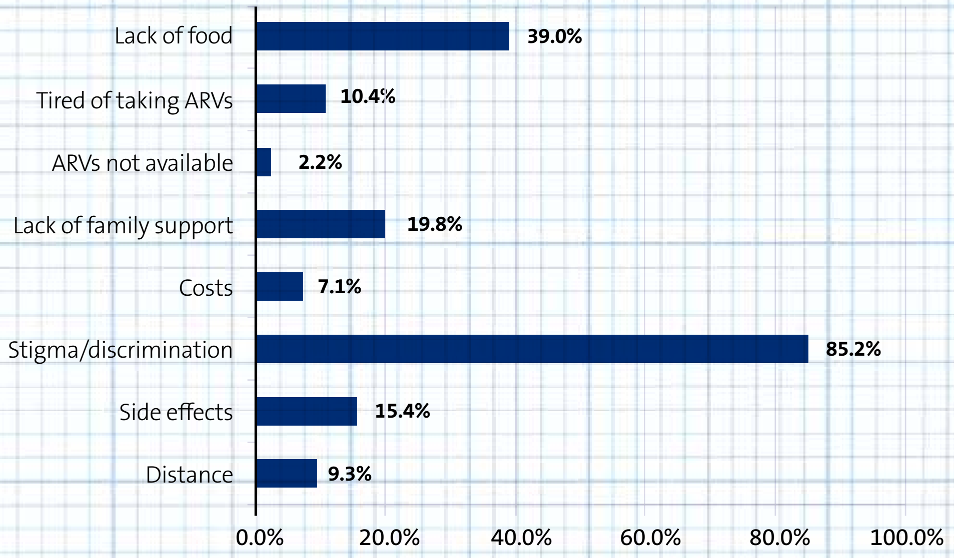
Timeframe	Number	%
Immediately	316	48.5%
0 - 3 months	84	12.9%
3 months - 1 year	101	15.5%
1 - 2 years	54	8.3%
2 - 5 years	52	8.0%
> 5 years	39	6.0%
don’t remember	6	0.9%

When asked why they started ART, 76.2% of the 652 participants said to stay healthy, 52% to alleviate symptoms, 18.6% advised by health care worker, 8.1% to minimise risk to partner, 8% for prevention of mother to child transmission (PMTCT) and 7.8% with advice from expert client.

Of the participants on ART (652), 27.9% thought it was difficult for people to take ARVs and 25.2% admitted to not have taken their ARVs when they were supposed to. The reasons for difficulty were stigma and discrimination (85.2%), lack of food (39%), lack of family support (19.8%), side effects (15.4%), tiredness of taking ARVs (10.4%), distance (9.3%), costs (7.1%) and unavailability of ARVs (2.2%). The reasons why makes it difficult ta defaulting were forgetting (69.5%), running out of stork (6.1%) and leaving medication at home or work (29.3%) as seen in **figure 4.**

Figure 4: Reasons for difficulty in taking ARVs (n=183)

Note: Multiple responses were possible



For participants not on ART (267), the results indicated that 10.1% have been on ART and stopped. 64.4% were on Pre-ART while 34.1% were not on pre-ART. As a follow up, respondents were asked about the period taken to be enrolled to pre-ART after being diagnosed HIV- positive and 33.1% said they were enrolled the same day, 20.9% within a week, 23.8% within a month and 21.5% after a month. Participants who were neither on Pre-ART nor ART were asked their main reason for not enrolling; For those not in pre-ART, the majority (35.2%) said they did not have time to attend while 29.7% said were not offered pre-ART and 16.5% were not aware of pre-ART services **(figure 5).** Those not on ART yet eligible, the majority (46.6%) said the main barriers for not initiating ART was not having someone telling them to and 38.4% said it was because of not feeling sick while 15.1% sighted lack of capacity of health staff (before implementation of Nurse-led ART initiation in Swaziland (NARTIS)) **(figure 6).**

Of the 824 participants that were in HIV care (652 ART and 172 pre-ART), 64.2% said they had an active treatment supporter, while 12.6% said they had supporters who were not providing the necessary support. Among the participants 23.5% had no treatment supporter because they were not aware of what a treatment supporter was (31.4%), they don't need one (19.6%), didn't know who to choose (15.5%), had one that has relocated (10.8%), never asked to choose one (9.8%) and purposefully gave wrong information out of fear of discrimination (5.2%).

Figure 5: Main reason not enrolled in pre-ART

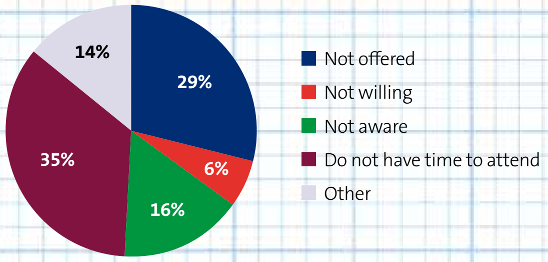


Figure 6: Main barrier that best explains the reason for not enrolling or receiving ART support at a health facility

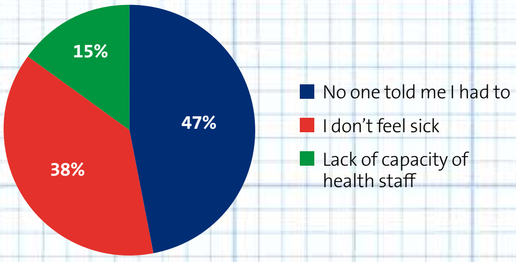


Figure 7: Do you consider yourself as ever having belonged to any of these groups? N=919

Note: Multiple responses were possible

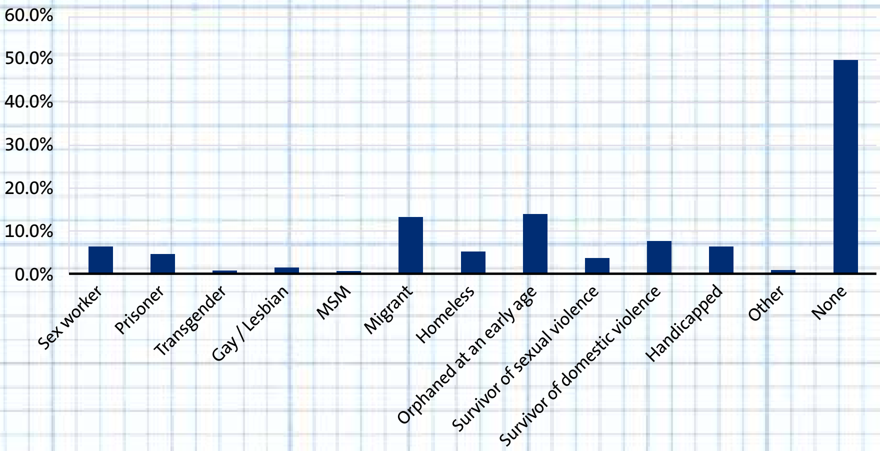
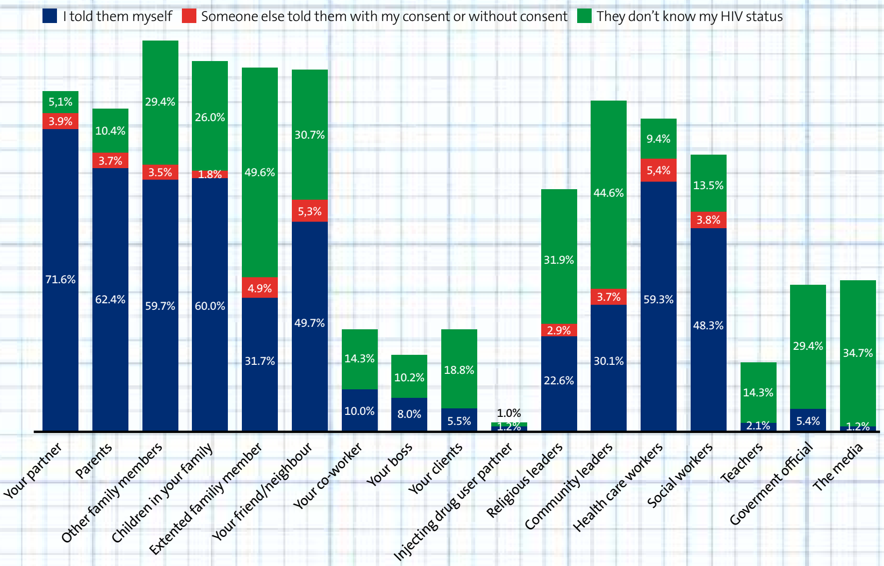


Figure 8: How other people got to know about participants' HIV status?



3.5. Human rights

The full realization of all human rights and fundamental freedoms for all is an essential element in the response to HIV prevention, treatment, care and support. A lack of respect for human rights fuels the spread and exacerbates the impact of the disease. To understand human rights issues for PLHIV in Swaziland, the study focused on consideration of oneself as ever belonged to a group that might not be necessary conventional to society, how PLHIV got to know about their HIV status, areas of life where PLHIV would say they have experienced the most discrimination because of their HIV status, why they didn't do anything to respond to the discrimination, institutions they think could help them confront discrimination and knowledge of any laws in the country that protect them from discrimination as a persons living with HIV.

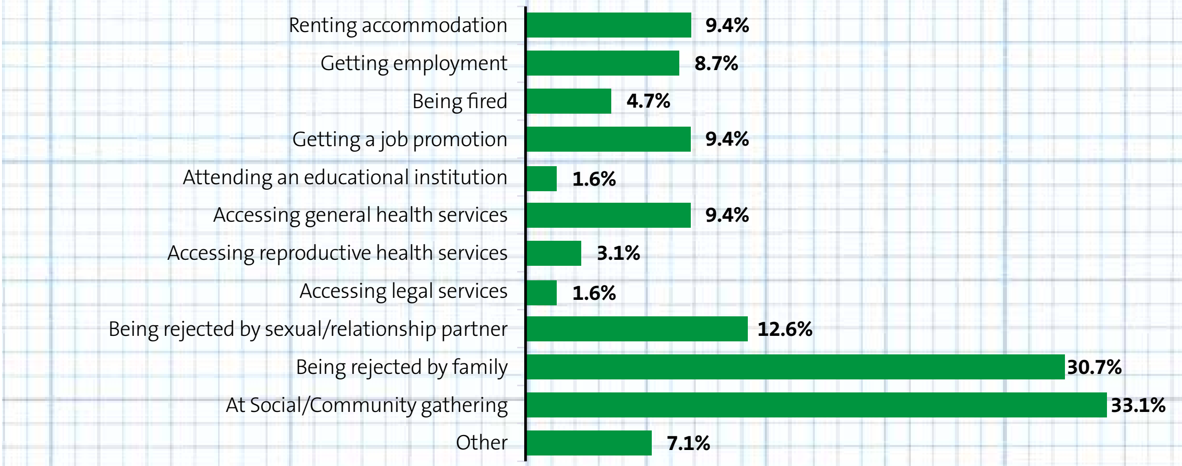
Membership to specialized group

When participants were asked if they considered themselves as ever having belonged to any of the groups indicated in **figure 7,** 49.8% respondents said they did not consider themselves to belong to any of these, whilst of those that belonged said they were orphaned at an early age (14.1%) and 13.3% were migrants.

Disclosure

Figure 8 indicates that most people disclosed their HIV status to partners, parents, family members and health care and it plausible that very few people had their status disclosed by someone else with or withouth their consent. It is worrying though to see that there are those who still do not disclose their status especially to family members and health care workers.

Figure 9: In the last 12 months, in what areas of your life would you say you have experienced the most discrimination because of your HIV status? (n=127)



Discrimination

When participants were asked if they had experienced any form of discrimination in the last twelve months, most (83.8%) said no while 13.8% said yes. This is a cause for concern and needs urgent action if the country is to achieve the vision of 'getting to zero'. Of those who had experienced discrimination because of HIV status in the last month, 33.1% reported to have experienced it in social gatherings, 30.7% were rejected by family while 12.6% were rejected by sexual/relationship partner. Other areas where respondents reported to have experienced discrimination included renting accommodation, getting employment, getting job promotion and accessing general health services as indicated in **figure 9.**

Table 11: Why did you not do anything to respond to this discrimination? (n=51)

Reasons for not responding to discrimination	Number	%
I was afraid	14	27.5%
I didn't know where to go	24	47.1%
I didn't know what to do	13	25.5%
I didn't think it would make any difference	9	17.6%
I didn't want (more) people to know about my diagnosis	1	2.0%
I t thought it was normal	2	3.9%
Other	1	2.0%

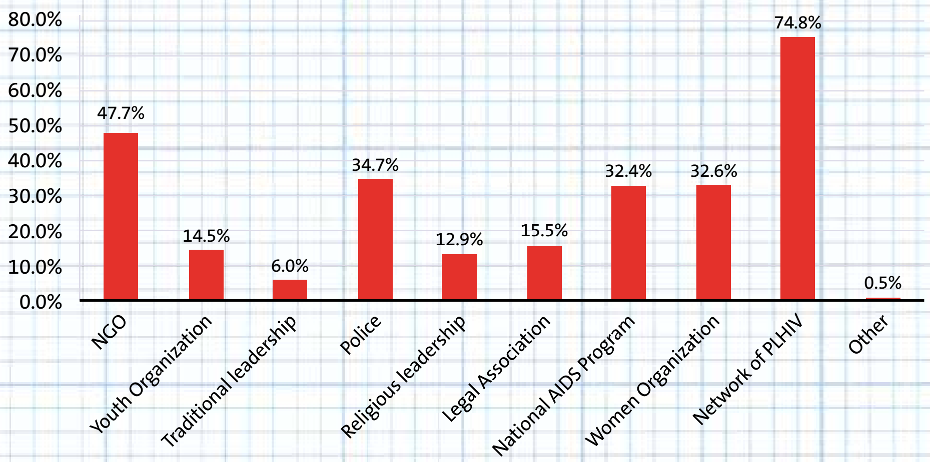
Actions taken in response to discrimination

Having been discriminated (n=127) the results indicate that 40.2% of the participants did not take any action to respond to the discrimination mentioned above. Only a small number confronted the perpetrator(s) directly (15.7%) or sought legal redress (11.0%), or tried to sensitize those involved (12.6%) and/or shared with HTC counsellor (15.7%).

Of those who did not do anything, 47.1% reported not knowing where to go, while 27.5% were afraid, 25.5% did not know what to do and 17.6% did not think it would make any difference as shown in **table 11.**

Figure 10: Which of the following institutions do you think could help you confront discrimination (n=919)

Note: Multiple responses were possible



Institutions that could help confront stigma

When asked which institutions they think would help confront stigma, 74.8% thought the Network of PLHIV could help while 47.4% thought other NGOs could address discrimination. Only 6% of the participants thought traditional leaders would help confront stigma as shown in **figure 10.**

Access to legal services

Twenty four percent (24%) of participants reported having access to free legal services and 57% do not have access to free legal services. When asked to list rights they have as PLHIV, a majority mentioned the following rights; right to health (n=790), right to work (n=636), right to marry and have a family (n=566), right to privacy (n=425) and right to education (n=314 respondents) as shown in **table 12.**

Table 12: Rights of PLHIV listed by respondents

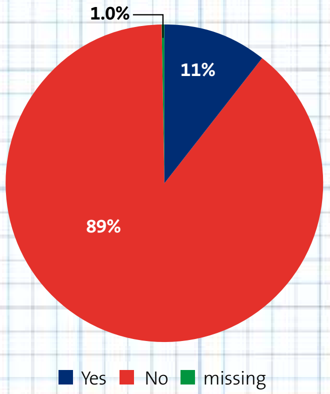
Note: Multiple responses were possible

Can you list any of the rights that you have as a person living with HIV?	# of respondents
Right to health	790
Right to education	314
Right to marry and have a family	566
Right to privacy	425
Right to work	636
Other	43

Laws that protect PLHIV

A majority of the participants (n=819, 89%) did not know of any laws in the country that protects them from discrimination as PLHIV as shown in **figure 11.**

Figure 11: Awareness of laws that protect PLHIV from discrimination? N=919



3.6. Prevention of new infections

HIV-related stigma and discrimination discourages individuals infected with and affected by HIV from accessing health and social services and this, in turn, contributes to the vulnerability of others to infection. When an open and supportive environment exists for those infected with HIV; they are protected from discrimination, treated with dignity, and provided with access to treatment, care and support; individuals are more likely to seek testing in order to know their status. In turn, those people who are HIV positive may deal with their status more effectively, by seeking and receiving treatment and psychosocial support, and by taking measures to prevent transmission to others, thus reducing the impact of HIV on themselves and on others in society.

To appreciate HIV prevention patterns amongst PLHIV, the study focused on understanding who people living with HIV thought was responsible for preventing HIV transmission, frequency of engaging in sexual activity by PLHIV, use of a condom, reasons for not using a condom, actions taken to prevent the transmission of HIV with regular partners and occasional partners, understanding of the prevention aspect of ART and frequency of alcohol use prior to engaging in sexual intercourse.

Responsibility of preventing HIV transmission

When the participants were asked who they thought was responsible for preventing HIV transmission, 48.7% said both partners were equally responsible, 38.1% said each person was responsible for their own lives, 7.8% said the PLHIV were fully responsible as shown in **table 13.**

Table 13: In a sexual relationship/encounter, who do you think is responsible for preventing HIV transmission? N=919

Responsibility of HIV prevention	Frequency	%
Each person is responsible for himself/herself	350	38.1%
Me and my sexual partner are equally responsible	448	48.7%
Am more responsible because I am HIV positive	46	5.0%
I am 100% responsible because I am HIV positive	72	7.8%
Missing	3	0.3%

Condom use

Sixty one percent (61%) of the participants reported having engaged in sexual intercourse in the past 6 months. Of those engaging in sexual intercourse, 52.0% reported doing so a few times a month while 40.9% reported engaging a few times a week as shown in **figure 12.** When asked how often they use a condom when engaging in sexual activity, 79.2% said most of the time while 15.4% said sometimes as shown in **figure 15.**

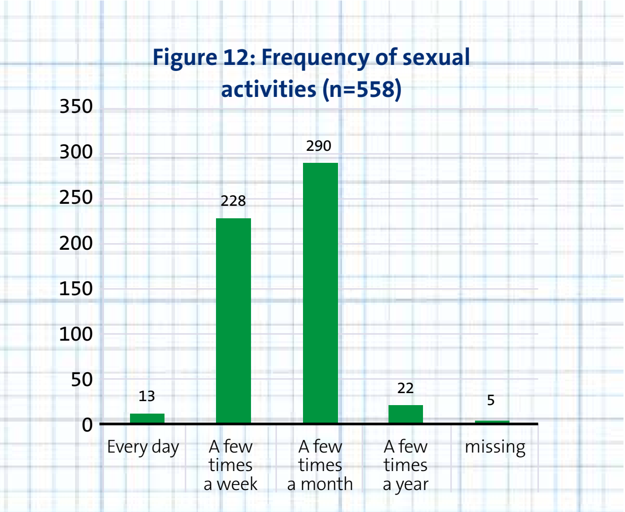


Figure 12: Frequency of sexual activities (n=558)

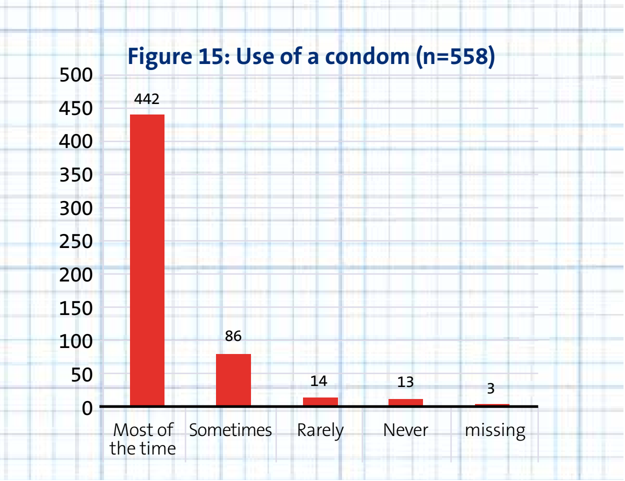


Figure 15: Use of a condom (n=558)

91.2% Of the participants reported having used a condom in the last sexual encounter while 6.1% reported not to have used a condom. Of 34 participants who reported not having used a condom, 11 said they did not have the condom right there, 6 said a condom is too uncomfortable while 6 indicated that condoms affect sexual performance/intimacy and 3 indicated that they wanted to get pregnant or wanted the partner to get pregnant. Others barriers indicated were inaccessibility of condoms, partner also living with HIV, trusts sexual partner, condoms not effective, partner insisted on not using a condom or partner not wanting to use a condom. None reported partner's circumcision or lack of knowledge on how to use a condom as a barrier as shown in **table 14.**

Table 14: Reasons for not using a condom (n=34)

Reason for not using a condom	Number of participants	%
No knowledge of where to get condoms	1	2.9%
Condoms not accessible	2	5.9%
Did not have a condom right then	11	32.4%
Cost too much	1	2.9%
Too uncomfortable	7	20.6%
Condoms not effective	3	8.8%
Condoms affect erection	3	8.8%
Condoms affect sexual performance/ intimacy	6	17.6%
Respondent wanted to get pregnant/ wanted the partner to get pregnant	3	8.8%
Trusts sexual partner	2	5.9%
Partner also living with HIV	2	5.9%
Do not know how to use the condom	0	0.0%
My partner is circumcised we need not use a condom	0	0.0%
Partner insisted on not using	2	5.9%
Partner do not want to use condom	3	8.8%

Four hundred and eighty seven (87%) participants indicated that their last sexual partner was a regular partner. The use of condoms to prevent transmitting HIV with a regular partner was high (96.4%) compared to the use of condoms to prevent transmitting HIV with an occasional partner (48.7%) as seen in **figures 14 and 15.** Disclosure of HIV status was slightly low (19%) with occasional partner compared to regular partner (49.1%). However, Only 6 participants out of the sample (n=558) indicated having disclosed their HIV status to their last sexual partners indicating very low levels of disclosure to sexual partners in general.

A majority of respondents (92%) indicated that they get information on how to prevent HIV transmission from clinics, hospitals, mass media, and PLHIV groups/ organizations.

Figure 14: Actions taken to prevent the transmission of HIV with your regular partner (n=558)

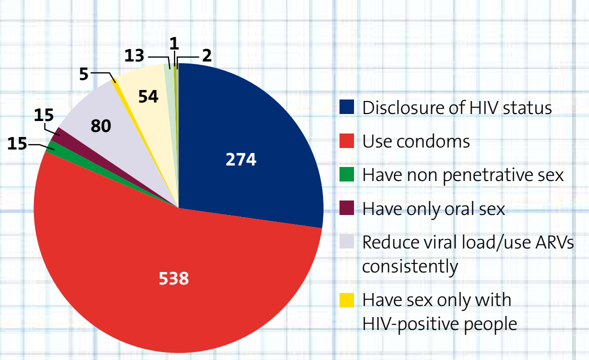
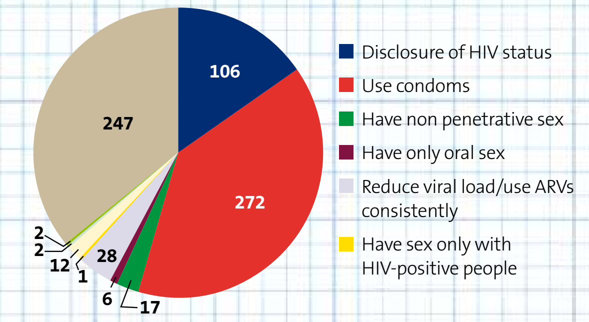


Figure 15: Actions taken to prevent the transmission of HIV with your regular partner occasional partner (n=558)

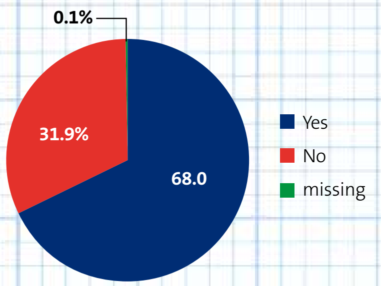


STIs and prevention of transmission

Also worth noting is that 14.5% (n=558) of the participants had acquired a sexually transmitted infection since being diagnosed HIV positive. When asked about action taken to prevent the transmission of HIV with regular partner; 538 (96.4%) of the respondents said they use condoms **(figure 14).**

When asked if they knew that individuals were less likely to transmit HIV under these conditions (adhering to ART treatment, having a low viral load for at least 6 months, and having no STIs), 68% respondents indicated that they were knowledgeable as shown in **figure 16.**

Figure 16: Did you know that individuals were less likely to transmit HIV under these conditions (adheres to ART treatment, has a low viral load for at least 6 months, and has no STIs)? n=919



Alcohol and substance use

Most participants (88.8%) indicated not having used any illegal substance in the past 12 months, 80.6% reported never getting drunk; and 3.9% respondents indicated always using alcohol before engaging in sexual intercourse as shown in **table 15.**

Table 15: How often do you use alcohol prior to engaging in sexual intercourse?

	Frequency	%
Always	36	3.9%
Most times	17	1.8%
Sometimes	64	7.0%
Never	799	86.9%
Missing	3	0.3%

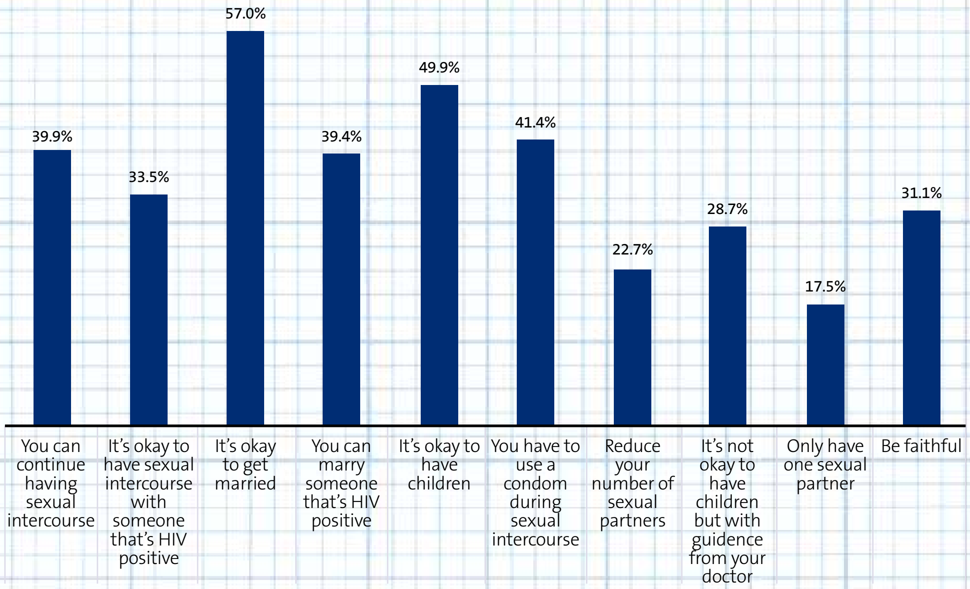


Figure 17: Main messages received from health care professionals about the management of your sexual life as PLHIV (n=790)

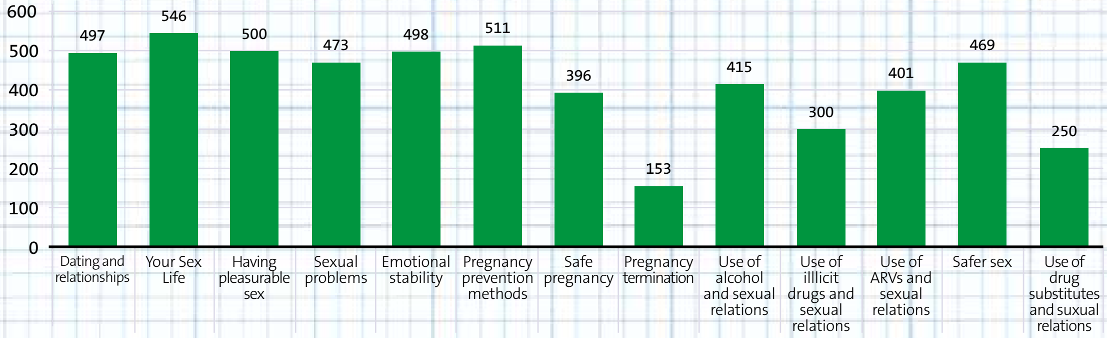


Figure 18: Had discussion with a health care professional(s)/counsellor(s) on any of the following subjects? (n=790)

Note: Multiple responses were possible

3.7. Sexual and reproductive health and rights

People Living with HIV have the right and freedom of choice regarding consensual, pleasurable and enjoyable sexual life; the right to intimacy, to have children, and to love. Further, HIV positive people also have the fundamental right to access sexual and reproductive health services without fear of being stigmatized or judged for their sexual and reproductive health choices.

To establish sexual and reproductive health and rights (SRHR) for PLHIV in Swaziland, the study focused on the right to sex and sexual life for PLHIV, the right to having children and the right to prevention of mother to child transmission (PMTCT) services which includes family planning, pregnancy and delivery and counselling on PMTCT.

Sex and sexual life

Six hundred and seventy six (73.6%) participants said they thought PLHIV have a right to have sex. When asked what messages they had received from healthcare professionals about the management of their sexual lives, slightly more than half said they were told that it is good to get married; 49.4% were told that it's possible to have children and 41.4% were told that they have to use a condom when having sexual intercourse. Only one participant was told to terminate pregnancy and none of the participants reported not having received any message about the management of their sexual lives shown in **figure 17.**

A majority of participants indicated that they had a discussion with a healthcare professional on their sex life, having a pleasurable sex life and pregnancy prevention options as shown in **figure 18.**

Bearing children

Also, 76.8% of the participants had children and 72.1% of these did not wish to have children in future. Of those who would like to have children in future (n=207); as indicated in **figure 19,** 46.9% indicated that they had received information on lowering viral load to undetectable levels and 46.1% on timed intercourse [unprotected intercourse during ovulation] as options for having children as PLHIV. More than half of the respondents indicated having received information about both the positive and negative effects of ARVs during pregnancy on baby and mother as shown in **table 16.**

Figure 19: Would you like to have children in future?

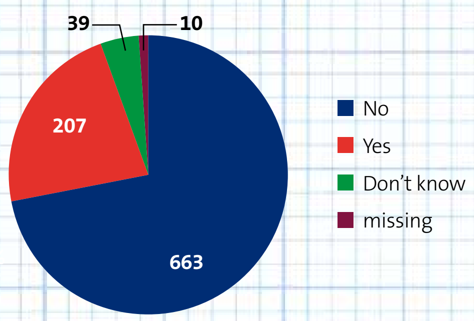


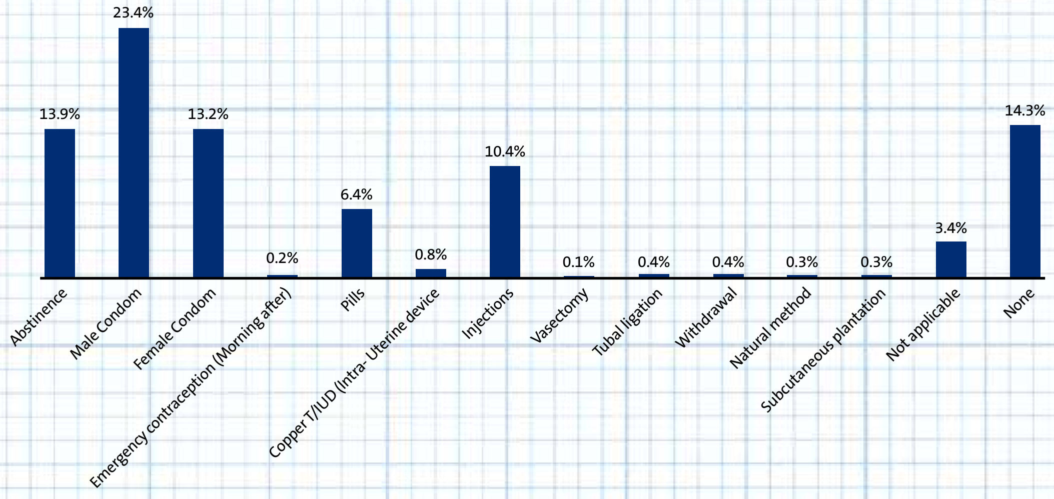
Table 16: Info on options for having children (n= 256)

Have you received any information on the following options for having children as a person living with HIV?	%
Lowering viral load to undetectable levels with ART	46.9%
Timed intercourse [unprotected intercourse during ovulation]	46.1%
Insemination with partner's semen	18.4%
Insemination with donor's semen	11.3%
Semen-washing	12.5%
In vitro fertilization	7.0%
Surrogacy	6.3%
Adoption	24.2%

Family planning

A majority of the total participants (87.9%) knew that male condoms prevent pregnancy, while contraceptive pills, female condoms, and abstinence were listed by 54.3%, 48.3%, and 40.6% respondents respectively. There were 14.3% respondents who reported not using any contraceptive method to prevent pregnancy. Male condoms were the most common, 23.4% indicated using them to prevent pregnancy as indicated in **figure 20.**

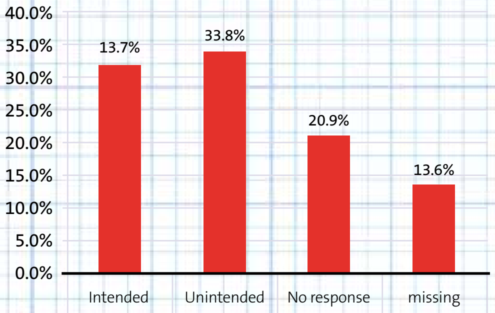
Figure 20: Are you currently using any contraceptive method to avoid/prevent pregnancy?(n=919)



Pregnancy and delivery

Of the 640 female participants in the study, 47.7% reported having given birth to a child since their diagnosis. There was no significant difference in number of women whose last pregnancy was intended compared to those that had unintended pregnancies (31.7% versus 33.8% respectively, N=640) as shown in **figure 21.** Four hundred and twenty four women (66.3%) were assisted by a healthcare professional with the delivery of their last pregnancy while 76 were not assisted. A majority of the women (72.5%) had natural births and 8% had caesarean section. Of those who gave birth through caesarean section, 72.5% reported that it was not by their own choice.

Figure 21: Would you say your last pregnancy was intended or unintended? N=640

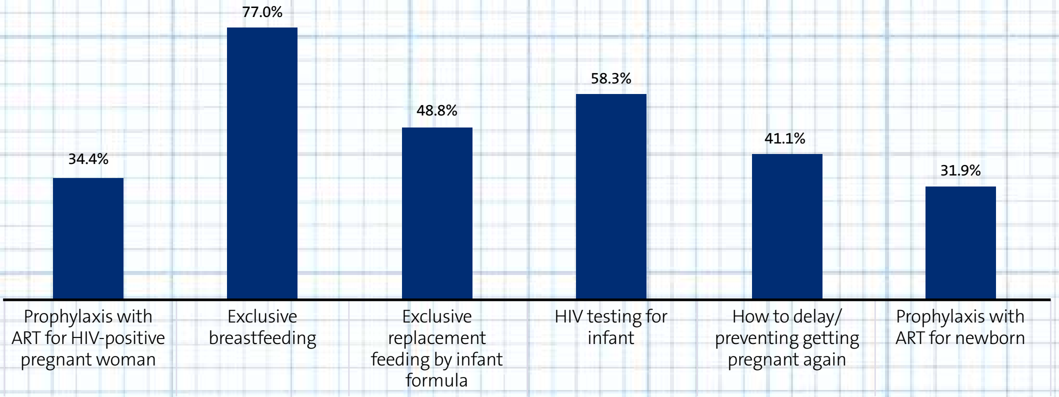


Counselling on Prevention of Mother to Child Transmission of HIV

Seventy seven percent (77%) of the women reported to having received counselling from a health care worker on exclusive breastfeeding, and only 31.9% women reported having been counselled by a health professional on prophylaxis for their newborn. More than half of the women indicated not having received counselling on HIV testing for the infant as shown in **figure 22.** Since delivery, 24.3% indicated not using any contraceptive method while only 28.2% indicated using a male condom. Sixty nine percent (69%) of the women using any form of contraceptive indicated that they did not choose that method themselves.

Figure 22: During the pregnancy and/or immediately after the birth of the baby, did you receive any counselling from a health professional? N=706

Note: Multiple responses were possible



3.8. Social and economic support

HIV incidence and disease outcomes are related to social and economic situation factors. Significantly within PLHIV there is diversity in social and economic support related to access to HIV care, the source of care and impact on sickness and mortality rates among those infected. Monitoring the prevalence of social and economic factors and their individual contributions to the health outcomes of PLHIV has improved understanding not only of disease incidence and critical preventive interventions, but also access to appropriate care and treatment, and identified ways in which these can be improved.

To establish the level of social and economic support for PLHIV, the study focused on looking at participation of PLHIV in socio-economic activities in their organizations and perception of importance of affiliation or belonging to organizations of PLHIV.

Participation of PLHIV in their organizational activities

When asked about the services carried out by the network, civil society, support group or association they had mentioned earlier in the interview, the activities enlisted in **table 17** were mentioned. Most of the people mentioned areas that are more related to social support as compared to economic support areas with slightly more than half of the respondents (52.4%) specifying emotional/psychological support, 37.1% information on health, 23.6% spiritual/moral support and 19.4% HIV prevention support whilst 8.5% mentioned economic support and 4.6% capacity building.

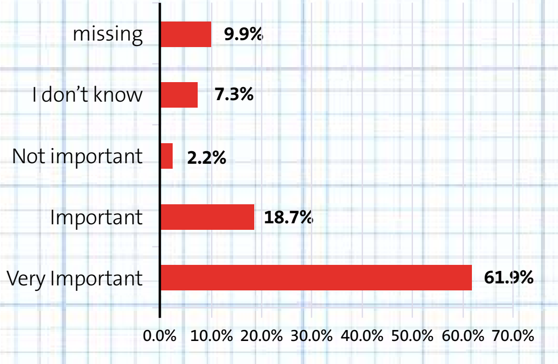
Importance of affiliating with Networks of PLHIV as seen by PLHIV

When asked to rate how important they would say it is to belong to a network of people living with HIV, 569 participants (61.9%) thought it was very important, 172 (18.7%) thought it was important while 20 participants (2.2%) thought it was not important **(figure 23).**

Table 17: What type of services and/or activities does the organisation carry out? N=489

Service	%
Provides emotional/psychological support	52.4%
Provides referrals to other services	18.3%
Provides physical care	18.7%
Provides information on health	37.1%
Provides spiritual/moral support	23.6%
Provides legal support	2.5%
Provides HIV prevention support	19.4%
Provides economic support	8.5%
Capacity building	4.6%
Helps to foster friendship	1.5%
Empowerment	10.0%
Fosters solidarity	0.3%
I don’t know	4.6%

Figure 23: How important would you say it is to belong to a network of PLHIV? N=919



4. Discussion

Demographic information of participants

The majority (92%) of the participants were from rural areas and only 8% were from urban areas. Whilst this correlates with the population distribution in the country, it may also be an indication that the people in rural areas have a higher rate of engagement and health-seeking behavior than their urban counterparts. This supports the need for decentralization of services closer to rural communities. Only 24.7% of the participants were above 50 years which means that most of the respondents were younger, potentially, more sexually-active people and this shows the need for continuous awareness-raising on issues of SRHR. In addition, 47% of participants reported to be married, and this calls for a greater understanding of gender dynamics and their impact on health and access to healthcare. The demographics of study participants are in line with the Swaziland population demography, where eight in ten of the Swazi population live in rural areas, with 44% of the total population is under the age of 15, and less than 4$is 65 years or older (). Having such a large number of PLHIV residing in the rural areas underscores the need to bring services closer to the community. There may be other factors that need further enquiry that result in people from rural areas demonstrating health seeking behaviour.

Empowerment

The Government of Swaziland through the Ministry of Health has demonstrated strong political will and commitment to address HIV. Programs like the decentralization of ART have significantly improved the survival rate and quality of life for PLHIV. In recent years, the role of PLHIV networks has significantly enhanced the national HIV response and this is helping to create a more favourable environment to advance the greater involvement of people living with HIV (GIPA) in all aspects of the response.

However, this study shows that the involvement of PLHIV at community level is still a challenge. Slightly more than half of PLHIV (53%) indicated they were affiliated with a civil society organization, support group or association. This means that policy makers have to devise means to reach and consult people that are not affiliated to support organizations to ensure that programmes are truly responding to the needs of all people living with HIV. These findings also challenge HIV support organizations and networks to continually innovate to be relevant to people's needs and be as representative as possible. Also noted was the involvement of PLHIV in the development of laws and policies that affect PLHIV (only 21%). This may be linked to the low affiliation rate which in turn maybe linked to the high stigma and discrimination rates. Countries like Moldova and South Africa (via the Stigma Index), found strong evidence of internalized stigma among PLHIV where the participants blamed themselves, felt ashamed or decided not to have children because of their HIV status (LPLHIV, 2013; NAPWA, 2013) while in Ethiopia the percentage of respondents who reported various forms of external stigma was high (NEP+, 2013). These results are almost similar to findings in Kenya, where a PHDP survey found that the level of PLHIV representation at policy-making level remained "remarkably" low (NEPHAK, 2012). In Zambia, only a tenth of respondents reported being involved in efforts to develop legislation, policies or guidelines relating to HIV and only 60% of respondents were unaware of national laws, policies or guidelines that protect the rights of people living with HIV, indicating minimal involvement of PLHIV in HIV legal and policy reform (NZP+, 2012).

Gender equality

According to the Extended National Strategic Framework on HIV& AIDS(eNSF)(2014- 2018), gender-based violence including sexual abuse remains a daunting challenge for Swaziland and its response to HIV and AIDS, particularly since gender based violence limits the ability of the abused person to negotiate for safer sexual acts, and often interferes with adhering to treatment.

This study showed that perceptions of abuse among PLHIV were higher than actual experiences of abuse i.e. psychological abuse by a sexual partner, being abandoned and denied sex by sexual partner were thought to be more likely to be experienced by PLHIV compared to HIV negative people. This may be linked to the high levels of self-stigma among PLHIV.

The study also noted most PLHIV did not do anything to respond to gender based abuse. Men were slightly more likely not to do anything (59%) compared to women (49%). Also, most PLHIV do not use available support services following the experiences of gender based abuse (67% men and 69% females).

In 2010, Swaziland passed a National Gender policy with a goal of mainstreaming gender into all areas of national development, including legislation, policies, programmes and projects, to ensure gender equity in HIV prevention, care, and treatment and support services.

Health promotion and access

Services Availability Mapping (2010) shows that 83% clinics and hospitals provide HIV testing and Counseling and the national HIV Testing and Counseling rate has improved from

16% in 2006/7 to 40% of people aged 15-49 being tested for HIV during the last 12 months preceding the Multiple Indicator Cluster Survey (MICS 2010). However, SHIMS (2012) shows that among persons who tested seropositive, only half of men (50%) were previously aware of their HIV status. This also concurs with the late testing percentage noted in this study. 42.6% PLHIV tested because they fell sick or were losing weight and 12.7% tested during hospitalization. Efforts to test people with unknown statuses should be strengthened as studies have estimated that "70% of new HIV infections are acquired from people who are undiagnosed" (Marks, G., et al 2010).

The country's ART coverage is high and HIV care services are free, however, efforts need to continue to be made to ensure that people are testing early and offered the choice to start treatment early. In this study 76.2% of PLHIV were on ART. However, barriers to adherence were also noted and a majority of PLHIV cited stigma and discrimination (85.2%) and lack of food (39%) as important barriers. A PHDP study in Mozambique also recorded almost similar challenges to ART adherence where 25% of survey participants mentioned inadequate food (Njihia, 2012). A similar study in Uganda (Walakira, 2012) recorded the following potential barriers to adherence lack of transport to access treatment (34%), not having enough food for drug regimen (32%) and ART side effects (23%). Such barriers need to be addressed to enable PLHIV to access services without fear, and economic projects should be supported and implemented to enable PLHIV to sustain themselves (Marks, 2006).

Human rights

Due to national and international efforts, important progress has been seen in the past few years in the areas of funding, expanding access to HIV prevention, treatment, care and support, and reducing HIV prevalence. However, the findings of this study show that there is still much needed action in the area of protecting the rights of PLHIV. Under the Constitution of the Kingdom of Swaziland of 2005, there is a non-discrimination clause in Section 14 clause 1 (a). Though this constitutional provision doesn't specifically mention HIV status, it states that everyone should be treated equally before the law.

This report has documented violations inflicted upon PLHIV because of their HIV status, mostly through being stigmatized and discriminated against. Noticeably was that most PLHIV did not take action to respond to discrimination. There are a number of reasons why PLHIV do not respond to such acts, including fear and lack of information, skills and knowledge regarding available protective laws. Hence legal aid, awareness campaigns and education about stigma and discrimination, as well as available legal protections should lie at the centre of advocacy work on the protection of human rights for PLHIV and an effective HIV response. Another critical issue that should be given adequate attention is the provision of legal assistance to PLHIV. Most of the alleged areas where PLHIV experience most discrimination are given adequate protection by the country's substantive labour and family laws. However, due to the unavailability of legal assistance services most PLHIV are forced to forfeit their rights.

Preventing new HIV infections

One of the critical guiding principles of PHDP is that "preventing new HIV infections is the shared responsibility of everyone irrespective of HIV status" (GNP+, 2011). This study shows that almost half of the PLHIV interviewed thought that both partners are equally responsible for preventing HIV transmission. However, there were 7.8% PLHIV who thought they were solely responsible for preventing HIV transmission. This study also reported high levels of condom use among PLHIV, 91.2% PLHIV reported having used a condom in the last sexual encounter. However, 6.1% reported not to have used a condom and the most reported reason being not having a condom right then. Condom use was also low with regular occasional partners (48.7%) compared to regular partners (96.4%).

Among sexually active PLHIV, 14.5% PLHIV had acquired an STI since being diagnosed HIV positive and 3.9% indicated always using alcohol before engaging in sexual intercourse. This study shows that prevention efforts among PLHIV are paying off. However, risky behaviors are still present among PLHIV and as such there is strong need to strengthen PHDP interventions among PLHIV as well as in care and treatment settings. These findings pose a challenge to policy makers, programmers to strengthen the integration of HIV prevention services into care and treatment setting.

Disclosure of HIV status to a steady partner as means of preventing HIV transmission was high compared to disclosure to an casual partner (49% vs. 19%). However, overall disclosure to last sexual partner was very low at 1%. This may be linked to the high levels of stigma and discrimination and high perception of gender-based violence against PLHIV compared to HIV negative people.

Sexual and reproductive health and rights

Reproductive health counselling plays an important role in the effectiveness of HIV prevention on strategies, particularly those focusing on vertical transmission and HIV-discordant couples. In 2009 an estimated 2,300 infants became infected during pregnancy, delivery and breastfeeding, indicating that PMTCT interventions prevented 59% of HIV infections in infants born to HIV-infected mothers (Kingdom of Swaziland, 2011).

Counselling on sexual and reproductive health is central to services aimed at preventing mother to child transmission of HIV. Counselling on PMTCT was noted to be low among PLHIV in this study i.e. 77% indicated not having received counselling on exclusive breastfeeding from a healthcare worker and only 6.6% were counselled on prophylaxis for the newborn.

In the study, about 22% PLHIV indicated that they would like to have children in future Similar responses were noted in Uganda (Walakira, 2012), where nearly a third (31%) of participants expressed a desire to have children in future. Also the levels of unintended pregnancies were noted to be high among PLHIV which is in line with national statistics where 63% women living with HIV have unmet needs for family planning (ANC 2010 in eNSF 2014-2018). This calls for strengthened efforts towards the integration of Family Planning and HIV care services in order for PLHIV to have increased access to family planning services and strengthening of the PMTCT program.

Social and economic support

A multisectoral approach that includes economic security, housing, and social services needs is as necessary to support the Positive Health, Dignity and Prevention Framework as the more obvious health-related building blocks. This study shows that most PLHIV organizations have more activities focusing on social support, especially emotional/psychological as compared to economic support. This shows that there are very few activities focusing economic support for PLHIV. Activities that provide economic support should be increased to reduce barriers for accessing services and to improve ART adherence.

5. Key findings and recommendations

Key findings	Recommendations
Empowerment	
53% society affiliation rate of PLHIV with networks and other key bodies created for their benefit	PLHIV service providers and networks should be strengthened to continually devise strategies to remain relevant and responsive to the changing needs of their constituencies. **Service providers should strengthen/improve the meaningful, coordinated and collective participation of PLHIV in the formulation of evidence-informed policies, strategies, and services.** Improve availability of services where PLHIV can go to when their rights are being violated, and empower PLHIV to take action against discrimination and improve rights literacy. **Expected outcomes:** - Evidence-informed policies, strategies, and services for PLHIV - Improved participation of networks of PLHIV in coordinating bodies in the response to HIV (national, regional and local community) Improved participation of PLHIV in the response to HIV at all levels evidenced by self-empowerment, visible PLHIV leadership and rights and treatment literate PLHIV populations and programmes. - Improved accountability and sustainability of networks of PLHIV through strengthened capacity in management and leadership development
A majority of participants (40%) did not take any action to respond to the discrimination they faced	
79% of participants have never been involved in development processes for laws and policies that affect PLHIV.	
52% of participants that are aware of organizations or groups	
52% of participants have provided some form of support to other PLHIV	
Health promotion and access	
38.6% of respondents tested through PIHTC; 42.6% tested because of illness or weight loss	Service providers should scale up PIHTC and communities should be mobilised for HTC. Strengthen programmes that promote adherence and psychosocial support for PLHIV such as the involvement of expert clients, engagement of treatment supporters, support groups and RHMs. Explore alternative reminders such as automated SMS reminders and other health platforms. Government and other stakeholders to adequately fund and expand the PLHIV nutrition support and other socio-economic support programs. Health Providers and other key stakeholders to promote antiretroviral therapy as an element of combination HIV prevention as this seems to have significant secondary benefits Government should create the legal environment that allows all stakeholders to address stigma and discrimination related to HIV. **Expected outcomes:** - Improved health outcomes for PLHIV through early diagnosis, adherence to effective and appropriate treatment regimes, and treatment of opportunistic and co-infections.
38.7% refills antd clinical follow-up is conducted by Expert Clients	
47.9% of clients on ART feel follow-up care should only be when they fall sick	
27.9% of respondents on ART think it is difficult for people to take ARVs; 85.2% said because of stigma/discrimination, 39% because of lack of food	
25.2% of respondents on ART have missed doses; 69.5% because they forgot	
For clients not in care; 35.2% do not have time to attend, 29.7% were not offered pre-ART, 16.5% were not aware of pre-ART services	
For clients not ART yet eligible, reasons were not having someone telling them to (46.6%), not feeling sick (38.4%), and lack of capacity of health staff (15.1%)	
64.2% of clients in HIV care have a treatment supporter; of which 19.1% of Rx supporters do not provide necessary support	
For respondents without treatment supporters, 31.4% are not aware of what a treatment supporter is, 19.6% do not need one, 15.5% don't know who to choose	

Key findings	Recommendations
Gender equality	
Perceptions regarding the experiences and situations endured by PLHIV had no gender connotations	Government, PLHIV Networks and other stakeholders should take action/implement services to reduce gender inequality, and incorporate gender issues as part of a broader focus on preventing gender based violence and reducing stigma and discrimination of both women and men living with HIV and their families. **Specifically:** - Increase gender equity in HIV/AIDS programs and all service delivery; - Reduce violence and coercion in the provision of services; - Address cultural norms and behaviours that promote male domination; - Increase women's legal protection; - Increase women's access to income and productive resources. **Expected outcomes:** - Improvements in the level and quality of access to treatment, prevention, care and support for all PLHIV as a result of gender-responsive and -protective legal, policy environment and systemic structures and services. - Improved participation of women, girls, men who have sex with men and transgender PLHIV in their communities and in the response to HIV through empowerment and rights literacy.
Experiences and situations endured by PLHIV do have gender connotations.	
56% males and 49% females do nothing in addressing issues.	
67% males and 69% females do not utilize support services	
Human rights	
83.8% of respondents indicated that they had not experienced any form of discrimination in the last 12 months compared to 13.8% who had	Government, PLHIV networks and other stakeholders should capacitate PLHIV to understand basic human rights and legal remedies available to them; Government should promote and implement strategies to ensure basic human rights are protected. Governmental and civil society organizations that work on HIV should use a right-based approach in designing, implementation and evaluating their programs and projects. **Expected outcomes:** - Improved quality of lives of PLHIV and equitable access to prevention, treatment, care and support services resulting from human rights-based and protective legal, policy structures and services; - Less discrimination and fewer human rights violations faced by PLHIV.
40.2% of respondents did not take action to discrimination	
23.7% of respondents have access to free legal services	
89.1% respondents did not know of any law in the country that protects them from discrimination as PLHIV	

Key findings	Recommendations
Prevention of new HIV infections	
When asked how often they use a condom when engaging in sexual activity, 79.2% said most of the time while 15.4% said sometimes. 14.5% respondents have acquired a sexually transmitted infection since diagnosed HIV positive.	Service providers should promote and strengthen couples HTC and partner counselling and testing. Service providers should continue promoting correct and consistent use of all condoms (female, male, dental dams etc) and ensure availability and access to condoms. Social Behavioral Change Risky behaviour counselling among PLHIV should be incorporated in ART clinics and community level. Service providers should raise awareness of the risks associated with alcohol consumption in the context of HIV transmission. **Expected outcomes:** - Improved sense and understanding of the shared responsibility for transmission and exposure among HIV-positive and HIV-negative populations; - Reduction in the number of sexually transmitted diseases as a result of increased and correct condom use;
91.2% respondents reported having used a condom in the last sexual encounter while 6.1% reported not to have used a condom.	
Of 34 who reported not having used a condom, 11 said they did not have the condom right there	
The use of condoms to prevent transmitting HIV with a regular partner was high (96.4%) compared to the use of condoms to prevent transmitting HIV with an occasional partner (48.7%).	
Disclosure of HIV status was slightly low (19%) with occasional partner compared to regular partner (49.1%).	
3.9% of respondents always alcohol before engaging in sexual intercourse	
Sexual and reproductive health and rights	
77% of the women reported not having received counselling from a health professional on exclusive breastfeeding	Government and other providers should strengthen integration and quality of HIV/Family Planning services: Increase the proportion of PLHIV made aware of sexual and reproductive health choices and services; Service providers should improve and increase counselling of PLHIV on the availability of services to reduce vertical transmission. **Expected outcomes:** - Improved health outcomes for women and men living with HIV through increased access to comprehensive sexuality education and quality and rights-based sexual and reproductive health services. - Reduction in the number of children born with HIV or infected in infancy.
Of those who would like to have children in future; 46.9% indicated that they had received information on lowering viral load to undetectable levels and 46.1% received information on timed intercourse [unprotected intercourse during ovulation] as options for having children as PLHIV.	
14.3% respondents reported not using any contraceptive method to avoid or prevent pregnancy.	
Male condoms were the highest as 23.4% indicated using them to prevent pregnancy.	
47.7% reported having had a baby/given birth to a child since their diagnosis.	
Social and economic support	
47.1% reported that they did not know of any organizations or groups that provide support services to PL HIV.	Government and all relevant stakeholders should invest in and support the development of networks and organisations that are relevant and respond to the needs of people living with HIV –Promote effective vertical and horizontal communication and coordination within networks of PLHIV in the country; Government and other funders/providers should support Income Generating Activities, for example through increased access to micro-credit facilities, organizing work groups. **Expected outcomes:** - Availability of services that respond to the needs of people as a result of strengthened participation of PLHIV in their communities (economic and social participation)
Slightly more than half of the respondents (53.2%) indicated that they belong to a civil society/support group/ association as a person living with HIV.	

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Annex 1: Positive Health, Dignity and Prevention Questionnaire

Interview for people living with hiv, ages 18 to 60 in Swaziland

(only to be conducted with individuals diagnosed at least 3 months prior to the interview)

Identification

000. **Respondent number**
Number..

000a. **Date**...

000bh. **End Time of Interview- HOUR**...

000bm. **End Time- MINUTE**..

000c. **Regiont**
☐ Manzini
☐ Hhohho
☐ Lubombo
☐ Shiselweni

000d. **Respondents residential location**
☐ Urban
☐ Rural

000e. **Place of recruitment**
☐ Care and treatment centre
☐ PLHIV group/network
☐ Health centre
☐ Household
☐ Laboratory
☐ Other..

000f. **Name of interviewer**...

000g. **Language used in interview**
☐ English
☐ Siswati
☐ Other..

Background Information

001. **Sex of respondent**

DO NOT ASK

☐ Male
☐ Female
☐ Transgender

002. **How old are you?**

age ....

003. **What religion do you practice?**

☐ Traditional
☐ Catholic
☐ Pentacostal
☐ Other Christian
☐ Muslim
☐ Other ....

004. **What is your current marital status?**

☐ Single (never married)
☐ Married
☐ Co-habiting (not married, living with partner)
☐ Divorced/ separated
☐ Widowed

005. **Who do you currently live with?**

Multiple responses possible

☐ Alone
☐ Children
☐ Partner
☐ Parents
☐ Siblings
☐ Other relatives
☐ Friends
☐ Spouse
☐ Other ....

006. **What is the highest level of education you have completed?**

☐ No schooling Go to question 008
☐ Lower primary school
☐ Upper primary school
☐ Lower secondary school
☐ Upper secondary school
☐ Vocational school
☐ College
☐ University
☐ Post-graduate degree
☐ Other ....

007. **Did you complete your studies and achieve your educational goals.**

☐ Yes Go to question 009
☐ No

008. **What is the main reason why you have not started or continued further with your studies?**

☐ I did not want to continue studying
☐ Family could not afford
☐ Got Married
☐ Too many domestic responsibilities
☐ Educational institution too far away
☐ Family does not approve
☐ Got pregnant
☐ Discrimination in educational setting
☐ Illness
☐ Not applicable
☐ Other ....

009. **Are you engaged in any activities to earn a living?**

☐ Yes
☐ No

010. **Which of these currently describes your employment status?**

Read out the answers

☐ Formal work
☐ Informal work
☐ Study
☐ Unemployed
☐ Retired

011. **Which of these statements best describe your present financial situation?**

Read out options

☐ I don’t have anything
☐ I have barely enough to get by
☐ I have enough to pay for the basics
☐ I am very comfortable

Health Promotion And Access

012. **How many years has it been since you were diagnosed as HIV-positive?**

☐ 3 Months to 1 Year
☐ >1 to 2 Years
☐ >2 to 3 Years
☐ >3 to 4 Years
☐ Over 5 Years
☐ Don’t remember

013. **Where did you go for your last HIV test?**

☐ VCT/New Start
☐ Government health facility
☐ Private health facility
☐ Outreach program/ Mobile testing
☐ Home-based testing (e.g through SHIMS)
☐ Blood Transfusion Service
☐ Other ....

013a. **How many times have you taken an HIV test?**

☐ Once
☐ Two times
☐ Three times
☐ Four times
☐ Five or more times
☐ Don’t remember

014. **Did you decide yourself to go get an HIV test, or did you accept a test upon the recommendation of a health provider?**

☐ Client-initiated
☐ Provider-initiated

015. **Why did you go for your first HIV test?**

Multiple responses possible

☐ Doctor's advice
☐ Happened during hospitalization
☐ Partner's risk behavior
☐ Own risk behavior
☐ Always falling sick/ losing weight
☐ Spouse/ partner positive
☐ Child positive
☐ Requirement of male circumcision
☐ Insurance requirement
☐ Employment requirement
☐ Visa requirement
☐ Antenatal clinic requirement
☐ Partner's illness
☐ Death of partner
☐ Pre-marital testing
☐ Military enrollment screening
☐ Other ……………………………………………………………………………………………………

016. **Did you receive pre- and post-test counselling when you were first tested for HIV?**

☐ I received both pre and post- HIV test counseling Go to question 018
☐ I only received only pre-test HIV counseling
☐ I only received only post-test HIV counseling
☐ I did not receive any counseling when I had an HIV test

017. **What was the main reason you did not receive both pre- and post-test HIV counselling**

☐ I did not want to receive counseling
☐ I did not know that it was available
☐ I did not have enough time
☐ Other ……………………………………………………………………………………………………

018. **Since your diagnosis, what changes (if any) have you noticed in relation to:**

Response	Has improved	Has gotten worse	Remains the same	Not applicable
Your health?	☐	☐	☐	☐
Your relationships with your family?	☐	☐	☐	☐
Your relationships with friends?	☐	☐	☐	☐
Your relationship with partner/spouse?	☐	☐	☐	☐
Your work place?	☐	☐	☐	☐
Society?	☐	☐	☐	☐

019. **Since you were diagnosed, what do you do to improve your quality of life?**

Multiple responses possible After respondent answers, probe by asking for any others Do not read out answers

☐ I practice sports
☐ I eat more healthy foods
☐ I have more fun
☐ I drink less alcohol
☐ I enjoy more with my family
☐ I don't smoke
☐ I have set new goals for myself
☐ I go to church/mosque more often
☐ I try to adhere to my treatment better
☐ I stopped using illicit drugs
☐ I don't do anything
☐ Other ....

020. **Since your diagnosis, have you ever had your CD4 count taken?**

☐ Yes
☐ No Go to question 024
☐ I Don't Know Go to question 024

021. **Did you receive the results?**

☐ Yes
☐ No Go to question 023

022. **What was your last CD4 count?**

Read options as respondent may not recall exact number, but may know the range

☐ Less than 200
☐ 200-350
☐ More than 350
☐ Don't Know/Don't remember Go to question 025

023. **What is the main reason why you did not get your CD4 results**

☐ Lack of time / too busy to return to get them
☐ The health facility lost the results
☐ I could not afford transport to return to the health facility
☐ I forgot to return to get the results
☐ I did not go to collect my results because of fear /reluctant
☐ Other ....

024. **Which of the following reasons explain why you have never had your CD4 count taken?**

Read out options

☐ No services
☐ I do not think it is necessary
☐ Did not know about CD4 count tests
☐ Too expensive (transport to get to health facility?)
☐ Other ....

025. **Is anti-retroviral treatment (ARVs/ART) for HIV available in health facilities near where you live?**

☐ Yes
☐ No Go to question 027
☐ Don't Know Go to question 027

026. **How long does/would it take you to travel to the nearest health facility where ART is available?**

☐ 15 minutes or less
☐ >15 minutes to 30 minutes
☐ >30 minutes to 1 hour
☐ >1 to 2 hours
☐ Over 2 hours
☐ Don't know

027. **Are you on ART?**

☐ Yes
☐ No Go to question 046

028. **How long have you been on ART?**

☐ 3 Months to 1 Year
☐ >1 to 2 Years
☐ >2 to 3 Years
☐ >3 to 4 Years
☐ Over 5 Years
☐ Don't remember

029. **After you were diagnosed HIV-positive, how long was it before you started ART?**

☐ Immediately
☐ <3 months
☐ 3 Months to 1 Year
☐ >1 to 2 Years
☐ >2 to 3 Years
☐ >3 to 4 Years
☐ Over 5 Years
☐ Don't remember

030. **Where do you receive your ART services (read at the options)**

☐ Government Facility
☐ Private practitioners
☐ Mission Health facility
☐ NGO owned Facility
☐ Industrial Owned facility
☐ Other……………………………………………………………………………………………

031. **What is the name of the health facility?** Only for those recruited from the Support groups

Health facility……………………………………………………………………………………

032. **What type of health facility is it?**

☐ Hospital
☐ Health centre
☐ Public health unit
☐ Clinic
☐ Mobile clinic
☐ Other……………………………………………………………………………………………

033. **How often are you required by your doctor or nurse to attend follow-up ART care?**

☐ Every two weeks
☐ Every month
☐ Every 2 months
☐ Every 3 months
☐ Every 6 months
☐ Other……………………………………………………………………………………………

034. **How often do you think it's necessary for you to attend follow-up ART care as a person living with HIV?**

☐ Every two weeks
☐ Every month
☐ Every 2 months
☐ Every 3 months
☐ Every 6 months
☐ Once a year
☐ When I fall sick
☐ Other……………………………………………………………………………………………

035. **From the moment you arrive at the ART health service facility (for your regular visits) until you leave, how long does it usually take?**

☐ One hour or less
☐ >1 to 2 Hours
☐ >2 to 4 Hours
☐ >4 Hours

036. **Which health provider do you see when attending the health facility for ART services (e.g. for initiation and/or refills/or PMTCT):**

Multiple responses possible | After respondent answers, probe by asking for any others | Do not read out answers

☐ Nurse
☐ Psychologist /Psychological counselor
☐ Phlebotomist
☐ Peer counselor
☐ Doctor
☐ Gynecologist
☐ Expert client
☐ Dentist /Dental hygienist
☐ Nutrition counselor
☐ Social worker
☐ I Don't Know
☐ Other ....

037. **Do you receive any services from the following, and how would you rate the quality of their support; excellent, adequate, or poor?**

Response	No support received	Excellent support	Adequate support	Poor support
Clinic-based expert client	☐	☐	☐	☐
Community-based expert client	☐	☐	☐	☐
Community-based volunteer	☐	☐	☐	☐

038. **What are the main reasons why you began to take ARVs?**

Multiple responses possible | After respondent answers, probe by asking for any others | Do not read out answers

☐ To stay healthy
☐ To alleviate HIV- related symptoms
☐ To minimize risk of transmission to partner
☐ To prevent transmission to child
☐ Was advised by health care provider
☐ Was advised by expert client
☐ Saw sexual partner taking ARVs, so assumed I was also positive
☐ Other ....

039. **Do you think it is difficult for some people to continue to take their ARVs?**

☐ Yes
☐ No Go to question 041
☐ Don't know Go to question 041

040. **In your own opinion, what are the reasons it is difficult for some people to continue to take their ARVs?**

Multiple responses possible

☐ Distance
☐ Side effects
☐ Stigma/Discrimination (If one is seen going to get ARVs)
☐ Costs
☐ Lack of family support
☐ ARVs not available
☐ Tired of taking ARVs
☐ Lack of food
☐ Any others? ....
☐ It is not difficult

041. **Have you ever shared ARVs with someone else (e.g., spouse/partner, children, etc.) for any reason?**

☐ Yes
☐ No Go to question 043

042. **What was the reason you shared your ARVs?**

Multiple responses possible

☐ Run out of stock
☐ Offer a ill person assuming that they are HIV positive
☐ Did not have money to collect my treatment
☐ My partner was sick and suspected he is also HIV positive
☐ Other ....

043. **Have you ever not taken your ARVs when you were supposed to (e.g. at work, or at home, etc.)?**

☐ Yes
☐ No Go to question 045

044. **What are the reason or reasons for you not taking your ARVs?**

Multiple responses possible

☐ I forgot
☐ I ran out of stock
☐ I forgot them at home/work
☐ Advised by traditional healer
☐ Advised by pastor/prophet
☐ Advised by family/friends
☐ I felt better
☐ I had travelled outside the country
☐ Too many side effects
☐ I was refused at health facility
☐ I could not access my usual health facility
☐ Health facility run out of stock

045. **Based on your experience accessing ARVs, would you say that when you came to the clinic, you were able to access ARVs always, most of the time, sometimes, rarely, or never?**

☐ Always
☐ Most of the time
☐ Sometimes
☐ Rarely
☐ Never

046. **Have you ever been on ART/ARVs for HIV?**

☐ Yes
☐ No

047. **Are you currently enrolled in pre-ART**

☐ Yes
☐ No Go to question 049
☐ Don't know what pre-ART is Go to question 049

048. **If enrolled in pre-ART, how long was the time period between when you were diagnosed as HIV-positive and when you were registered in pre-ART?**

☐ Same day
☐ Within a week
☐ Within a month
☐ Longer than a month
Go to question 051

049. **If not enrolled in pre-ART, what is the main reason you are not enrolled in pre-ART?**

☐ Not offered
☐ Not willing
☐ Not aware
☐ Do not have time to attend
☐ Other ....

050. **What is the main barrier that best explains the reason for your not enrolling or receiving ART support at a health facility?**

Multiple Options Do not read out
☐ Discouraged by family friends
☐ No money
☐ No one told me that I had to
☐ I don't feel sick
☐ I don't want people to know I am HIV+
☐ Lack of capacity of health staff
☐ Did not receive ART testing results
☐ Because of my religion
☐ Complicated procedures (at care and treatment centers)
☐ Discrimination in health centres
☐ Lack of chemical reactives and drugs
☐ Working hours of care & treatment centers not convenient
☐ Too far from where I live
☐ Other ....
Go to question 054

051. **Do you currently have a Treatment Supporter, i.e. a friend/family/colleague who supports you in receiving your pre-ART or ART services?**

☐ Yes
☐ Yes but not supported
☐ No Go to question 053

052. **How would you rate the quality of support that you receive from the treatment supporter: excellent, adequate, or poor?**

☐ Excellent support
☐ Adequate support
☐ Poor support
Go to question 053 if woman
Go to question 059 if man

053. **What is the main reason you do not have a treatment supporter?**

☐ I do not know what it is
☐ I was not given one
☐ I had one before but has relocated
☐ I purposely gave the wrong information in fear of stigma
☐ Other ....

054. **Are you currently pregnant?**

For women only For men, go to question 059

☐ Yes
☐ No Go to question 059
☐ I Don’t Know Go to question 059
☐ No response Go to question 059

055. **Do you take any kind of ART for you health and to prevent transmission to the baby?**

☐ Yes
☐ No
☐ Don’t Know

056. **In the last 6 months, have you received any of the following services?**

Multiple Options Do not read out

☐ CD4 count tests
☐ Viral load tests
☐ Adherence support
☐ STI screening
☐ PAP smear/Cervical cancer screening
☐ TB screening
☐ Psychological care
☐ Prophylaxis for opportunistic infections
☐ Blood formula (lymphocytes, liver,)
☐ Peer counselling
☐ Complementary exams for opportunistic infections
☐ Gynaecological examination
☐ Proctological examination
☐ Ultrasound
☐ Home-based cares

057. **Of the services received please indicate the service which was received for free?**

Multiple responses are possible Read out options

☐ CD4 count tests
☐ Adherence support
☐ Viral load tests
☐ STI screening
☐ PAP smear/Cervical cancer screening
☐ TB screening
☐ Psychological care
☐ Prophylaxis for opportunistic infections
☐ Blood formula (lymphocytes, liver,)
☐ Peer counselling
☐ Complementary exams for opportunistic infections
☐ Gynaecological examination
☐ Proctological examination
☐ Ultrasound
☐ Home-based cares

058. **Do you think that health centers keep the medical records relating to your HIV status confidentially?**

☐ Yes
☐ More or less
☐ No
☐ Don’t Know

Sexual & Reproductive Health and Rights

059. **Do you think that people living with HIV have the right to have sex?**

- ☐ Yes
- ☐ No
- ☐ Don't Know

060. **Since you were diagnosed as HIV-positive, what kind of messages have you received from health care professionals about the management of your sexual life?:**

Tick as appropriate Read out options

- ☐ You can continue having sexual intercourse
- ☐ Its okay to have sexual intercourse with someone thats HIV-positive
- ☐ Its okay to get married
- ☐ You can marry someone thats HIV-positive
- ☐ Its okay to have children
- ☐ You should not have sexual intercourse
- ☐ You have to use condoms during sexual intercourse
- ☐ Reduce your number of sexual partners
- ☐ If you are pregnant, have a C-section delivery
- ☐ Its okay to have children, but with guidance from doctor
- ☐ Only have one sexual partner
- ☐ Be faithful
- ☐ Do not have sexual intercourse while intoxicated
- ☐ Get sterilized to avoid pregnancy
- ☐ If you are pregnant, terminate the pregnancy
- ☐ You can deliver your infant vaginally
- ☐ You can access other forms of contraception (apart from condoms)

061. **In the last 12 months, have you had a discussion with a health care professional(s)/counsellor(s) on any of the following subjects?:**

Read out & circle as appropriate

Response	Yes	No	Not applicable	No response
Dating and relationships	☐	☐	☐	☐
Your sex life	☐	☐	☐	☐
Having pleasurable sex	☐	☐	☐	☐
Sexual problems	☐	☐	☐	☐
Emotional stability	☐	☐	☐	☐
Pregnancy prevention methods	☐	☐	☐	☐
Safe pregnancy	☐	☐	☐	☐
Pregnancy termination	☐	☐	☐	☐
Use of alcohol and sexual relations	☐	☐	☐	☐
Use of illicit drugs and sexual relations	☐	☐	☐	☐
Use of ARVs and sexual relations	☐	☐	☐	☐
Safer sex	☐	☐	☐	☐
Use of drug substitutes and sexual relations	☐	☐	☐	☐

062. **Do you have a child/children?**

☐ Yes
☐ No

063. **Would you like to have any children in the future?**

☐ Yes
☐ No Go to question 066
☐ Don't Know

064. **Have you received any information on the following options for having children as a person living with HIV?**

Read out

☐ Lowering viral load to undetectable levels with ART
☐ Timed intercourse [unprotected intercourse during ovulation]
☐ Insemination with partner's semen
☐ Insemination with donor's semen
☐ Semen-washing
☐ In vitro fertilization
☐ Surrogacy
☐ Adoption
☐ Other ....
☐ None

065. **Have you received information about both the positive and negative effects of ARVs during pregnancy on...**

Multiple responses are possible Read out answers

☐ The Baby?
☐ The Mother?

066. **How can pregnancy be avoided?**

Multiple responses possible After respondent answers, probe by asking for any others Do not read out answers

☐ Abstinence
☐ Male condoms
☐ Female condoms
☐ Emergency contraception/Morning after pills
☐ Contraceptive pills
☐ Copper T / IUD (intra-uterine device)
☐ Injections
☐ Vasectomy
☐ Tubal ligation
☐ Masturbation
☐ Withdrawal
☐ Natural method
☐ Subcutaneous plantation / Implant
☐ Lactational amenorrhea [i.e. continued breastfeeding to prevent next pregnancy]
☐ Don't Know

067. **Are you currently using any contraceptive method to avoid/prevent pregnancy?**

Multiple responses possible After respondent answers, probe by asking for any others Do not read out answers

☐ Abstinence
☐ Using male condoms
☐ Using female condoms
☐ Using emergency contraception/ Morning After
☐ Pills
☐ Copper T
☐ Injections
☐ Ovules
☐ Vasectomy
☐ Tubal ligation
☐ Withdrawal
☐ Natural method
☐ Subcutaneous plantation
☐ Lactation amenorrhea (i.e. continued breastfeeding to prevent next pregnancy)
☐ Not applicable
☐ None

068. **Since your diagnosis, have you had a baby/given birth to a child?**

For women only For men, go to question number 076

☐ Yes
☐ No Go to question 076

069. **Would you say your last pregnancy was intended or unintended?**

☐ Intended
☐ Unintended
☐ No response

070. **Who assisted with the delivery of your last pregnancy?**

☐ Doctor
☐ Midwife
☐ Nurse
☐ Relative
☐ Friend
☐ Traditional Birth Attendant
☐ No one
☐ Other ....

071. **Was it a natural delivery or was it a Caesarian birth?**

☐ Natural Go to question 073
☐ Caesarian

072. **Did you choose this method of delivery yourself?**

☐ Yes
☐ No

073. **During the pregnancy and/or immediately after the birth of the baby, did you receive any counseling from a health professional on:**

Read out options

☐ Prophylaxis with ART for HIV-positive pregnant women?
☐ Exclusive breastfeeding?
☐ Exclusive use of infant formula?
☐ HIV testing for the infant?
☐ How to delay/prevent getting pregnant again?
☐ Prophylaxis with ART for the newborn?

074. **Since the delivery, what method(s) of contraception have you been using, if any?**
Multiple responses are possible Read out options
☐ None
☐ Abstinence
☐ Using male condoms
☐ Using female condoms
☐ Using emergency contraception
☐ Pills
☐ Copper T
☐ Injections
☐ Ovules
☐ Vasectomy
☐ Tubal ligation
☐ Rhythm method
☐ Withdrawal
☐ Natural Method
☐ Subcutaneous plantation
☐ Lactational amenorrea
☐ No answer

075. **How did you choose this method?**
☐ I chose it myself
☐ I was advised by health staff
☐ I was advised by my partner/ family
☐ I Didn't have a choice
☐ Other (specify)..

Prevention of New Infections

Please remember that your answers are totally confidential and you are free to decide if you want to answer the following questions or not.

076. **In a sexual relationship/encounter, who do you think is responsible for preventing HIV transmission?**
Read out Circle only one
☐ Each person is responsible for himself/herself
☐ Me and my sexual partner are equally responsible
☐ Am more responsible because I am HIV positive
☐ I am 100% responsible because I am HIV positive

077. **Have you engaged in sexual intercourse in the past 6 months?**
☐ Yes
☐ No Go to question 086

078. **If you have engaged in sexual intercourse in past 6 months, how frequently do you engage in sexual activity?**
☐ Every day
☐ A few times a week
☐ A few times a month
☐ A few times a year

079. **On average, when you engaged in sexual intercourse, how often do you use a condom?**
☐ Most of the time
☐ Sometimes
☐ Rarely
☐ Never

080. **Since you were diagnosed, have you acquired any sexually-transmitted infection?**

☐ Yes
☐ No
☐ Don’t Know
☐ No response

081. **What do you do to prevent the transmission of HIV?**

Multiple responses are possible Read out options

With my regular partner	Yes	No
Disclosure of hiv status	☐	☐
Use condoms	☐	☐
Have non penetrative sex	☐	☐
Have only oral sex	☐	☐
Reduce viral load/Use arvs consistently	☐	☐
Have sex only with hiv-positive people	☐	☐
Limit number of sexual partners	☐	☐
Other	☐	☐
Not applicable	☐	☐

With my occasional partner	Yes	No
Disclosure of hiv status	☐	☐
Use condoms	☐	☐
Have non penetrative sex	☐	☐
Have only oral sex	☐	☐
Reduce viral load/Use arvs consistently	☐	☐
Have sex only with hiv-positive people	☐	☐
Limit number of sexual partners	☐	☐
Other	☐	☐
Not applicable	☐	☐

082. **The last time you had penetrative sex, did you and your partner use a condom?**

☐ Yes Go to question 084
☐ No
☐ Don’t remember Go to question 084
☐ Not applicable Go to question 084

083. **What are the barriers that best explain the reason for your not using a condom?**

Multiple responses possible | After respondent answers, probe by asking for any others | Do not read out answers

☐ No knowledge of where to get condoms
☐ Condoms not accessible
☐ Did not have a condom right then
☐ Cost too much
☐ Too uncomfortable
☐ Condoms not effective
☐ Condoms affect erection
☐ Condoms affect sexual performance/ intimacy
☐ Respondent wanted to get pregnant/ wanted the partner to get pregnant
☐ Trusts sexual partner
☐ Partner also living with HIV
☐ Do not know how to use the condom
☐ My partner is circumcised we need not use a condom
☐ Partner insisted on not using
☐ Partner do not want to use condom
☐ Other ....

084. **Was your last sexual partner a regular partner (husband/wife, long-term girlfriend/boyfriend) or occasional partner?**

☐ Regular partner
☐ Occasional partner

085. **Did you disclose your HIV status to your last sexual partner?**

☐ Yes
☐ No
☐ No response

086. **Since your diagnosis, where do you get information on how to prevent the transmission of HIV?**

Multiple responses possible | After respondent answers, probe by asking for any others | Do not read out answers

☐ HIV clinics
☐ People living with HIV groups/ organizations
☐ Non-Governmental Organizations
☐ Hospitals
☐ Peer Counselors
☐ Religious organizations
☐ Mass Media (radio or television)
☐ Nowhere (Not receiving any information)
☐ Other ....

087. **The likelihood of HIV transmission is reduced to nearly zero when an individual adheres to ART treatment, has a low viral load for at least 6 months, and has no STIs. Did you know that individuals were less likely to transmit HIV under these conditions?**

☐ Yes
☐ No

088. **You would be less likely to use condoms?**

☐ Yes
☐ No

089. **You would have higher numbers of sexual partners?**

☐ Yes
☐ No

090. **You would have high frequency of sexual activity?**

☐ Yes
☐ No

Please remember that your answers are totally confidential

091. **During the last 12 months, which of the following substances have you tried, if any?**

Multiple responses are possible Read out options

☐ Cocaine
☐ Marijuana
☐ Heroin
☐ Other ....
☐ None Go to question 100
☐ No response

092. **During the last 12 months, how often have you used these substances?**

☐ Once
☐ 2-10 Times
☐ More than 10 times

093. **Have you injected drugs since you were diagnosed?**

☐ Yes
☐ No Go to question 100
☐ No response

094. **How often do you use drugs prior to engaging in sexual intercourse?**

☐ Always
☐ Most times
☐ Sometimes
☐ Never
☐ No response

095. **Are you aware of any needle exchange programs available to those that inject drugs?**

☐ Yes
☐ No Go to question 097
☐ Don't Know

096. **Have you ever participated in a needle exchange program?**

☐ Yes
☐ No

097. **Do you have access to clean needles and syringes?**

☐ Yes
☐ No

098. **Do you have access to a drug rehabilitation program(s)?**

☐ Yes
☐ No

099. **Have you ever been denied anti-retroviral therapy (ART/ARVs) because of your drug use?**

☐ Yes
☐ No

100. **How often do you get drunk in a week?**

☐ Once
☐ 2 Days per week
☐ 3 Days per week
☐ 4 Days per week
☐ 5 Days per week
☐ 6 Days per week
☐ Daily
☐ Never

101. **How often do you use alcohol prior to engaging in sexual intercourse?**

☐ Always
☐ Most times
☐ Sometimes
☐ Never

Human Rights

102. **Do you consider yourself as ever having belonged to any of these groups?**

Read out

☐ Sex worker
☐ Prisoner
☐ Transgender
☐ Gay/lesbian
☐ MSM
☐ Migrant
☐ Homeless
☐ Orphaned at an early age
☐ Survivor of sexual violence/harrassment
☐ Survivor of domestic violence
☐ Handicapped
☐ Other
☐ None

103. **For each of the following people or groups of people, please describe how they were first told about your HIV status, if they have been told.**

Read out Please tick the answers

Only tick more than one box in each line if the answer is different for different individuals

Response	I told them	Someone else told them, WITH my consent	Someone else told them, WITHOUT my consent	They don't know my HIV status	Not applicable
Your partner	☐	☐	☐	☐	☐
Parents	☐	☐	☐	☐	☐
Other family members	☐	☐	☐	☐	☐
Children in your family	☐	☐	☐	☐	☐
Extended family members	☐	☐	☐	☐	☐
Your friends/neighbors	☐	☐	☐	☐	☐
Your co-workers	☐	☐	☐	☐	☐
Your boss(es)	☐	☐	☐	☐	☐
Your clients	☐	☐	☐	☐	☐
Injecting drug partners	☐	☐	☐	☐	☐
Religious leaders	☐	☐	☐	☐	☐
Community leaders	☐	☐	☐	☐	☐
Health care workers	☐	☐	☐	☐	☐
Social workers/counselors	☐	☐	☐	☐	☐
Teachers	☐	☐	☐	☐	☐
Government officials	☐	☐	☐	☐	☐
The media	☐	☐	☐	☐	☐

104. **What do you think would happen if you disclosed your HIV status?**
Multiple responses are possible Read out options

Response	Yes	No	Don't know	Not applicable
I would get fired	☐	☐	☐	☐
My partner would leave me	☐	☐	☐	☐
My family would abandon me	☐	☐	☐	☐
I would lose the right to inherit	☐	☐	☐	☐
I would be deported	☐	☐	☐	☐
I would be denounced	☐	☐	☐	☐
My children would be separated from me	☐	☐	☐	☐
I would be socially rejected	☐	☐	☐	☐
I would be expelled from school	☐	☐	☐	☐
I would get support	☐	☐	☐	☐
Other	☐	☐	☐	☐

105. **In the last twelve months, have you experienced any form of discrimination?**
☐ Yes
☐ No Go to question 109
☐ Don't Know Go to question 109

106. **In the last 12 months, in what areas of life would you say you have experienced the most discrimination because of your HIV status?**
Multiple responses are possible Read out options
☐ Renting accommodation
☐ Getting employment
☐ Being fired
☐ Getting a job promotion
☐ Attending an educational institution
☐ Accessing general health services
☐ Accessing dental care
☐ Accessing sexual health services
☐ Accessing reproductive health services
☐ Accessing legal services
☐ Being rejected by sexual/relationship partner
☐ Being rejected by family
☐ Accessing recreational/restaurant services
☐ At social/ community gatherings
☐ Other ....

107. **What kind of action did you take to respond to this discrimination?**
Multiple responses possible After respondent answers, probe by asking for any others Do not read out answers
☐ Confronted the perpetrator(s) directly
☐ Lodged a complaint in a civil society organization
☐ Sought legal redress
☐ Tried to sensitize those involved Go to question 109
☐ Shared with HTC counselor Go to question 109
☐ Other .... Go to question 109
☐ Didn't do anything

108. **Why didn't you do anything to respond to this discrimination?**

Multiple responses possible | After respondent answers, probe by asking for any others | Do not read out answers

☐ I was afraid
☐ I Didn't know where to go
☐ I Didn't Know what to do
☐ I Didn't think it would make any difference
☐ I Didn't want (more) people to know about my diagnosis
☐ I Just thought it was normal
☐ Other ....

109. **Which of the following institutions do you think could help you confront discrimination?**

Multiple responses are possible | Read out options

☐ NGO
☐ Youth Organization
☐ Traditional leadership
☐ Police
☐ Religious Organization
☐ Legal Association
☐ National AIDS Program
☐ Women Organization
☐ Network of people living with HIV
☐ Other ....

110. **Do you have access to free legal services?**

☐ Yes
☐ No
☐ Don't Know

111. **Can you list any of the rights that you have as a person living with HIV?**

☐ Right to health
☐ Right to education
☐ Right to marry and have a family
☐ Right to privacy
☐ Right to work
☐ Other ....

112. **Do you know of any laws in this country that protect you from discrimination as a person living with HIV?**

☐ Yes (Specify) ....
☐ No

Gender Equality

Would you say that people living with HIV are more likely to have experienced the following situations than HIV-negative people? Being...

Multiple responses are possible | Read out options

113a. **Physically abused by a sexual partner?**

☐ Agree
☐ Disagree

113b. **Abandoned by a sexual partner?**

☐ Agree
☐ Disagree

113c. **Denied financial support by a sexual partner?**

☐ Agree
☐ Disagree

113d. **Deliberately ignored (not talked to) by a sexual partner?**
☐ Agree
☐ Disagree

113e. **Denied sex by a sexual partner?**
☐ Agree
☐ Disagree

113f. **Denied the right to negotiate non-penetrative sex?**
☐ Agree
☐ Disagree

113g. **Denied the right to negotiate a contraceptive method?**
☐ Agree
☐ Disagree

113h. **Psychologically abused by a sexual partner (shouted at, insulted, despised, blamed)?**
☐ Agree
☐ Disagree

113i. **Forced to have sex against your will?**
☐ Agree
☐ Disagree

113j. **Forced to terminate your pregnancy?**
☐ Agree
☐ Disagree

113k. **Forced to be separated from your family (i.e., you cannot call or visit them)?**
☐ Agree
☐ Disagree

113l. **Being threatened by a partner?**
☐ Agree
☐ Disagree

114. **Since you were diagnosed, have you experienced any of these situations? Being...**
Multiple responses are possible Read out options
☐ Physically abused by a sexual partner?
☐ Denied financial support by a sexual partner?
☐ Deliberately ignored (not talked to) by a sexual partner?
☐ Denied sex by a sexual partner?
☐ Denied the right to negotiate non-penetrative sex ?
☐ Denied the right to negotiate a contraceptive method?
☐ Psychologically abused by a sexual partner (shouted at, insulted, despised, blamed)?
☐ Denied the right to negotiate the use of condoms?
☐ Forced to have sex against your will?
☐ Forced to terminate your pregnancy?
☐ Forced to be separated from your family (i.e., you cannot call or visit them)?
☐ Being threatened by a partner?

115. **What kind of action did you take to respond to this/these situation(s)?**
Multiple responses are possible Read out options
☐ Confronted the perpetrator(s)/person(s) responsible directly
☐ Lodged a complaint with a civil society organization
☐ Sought legal redress
☐ Tried to sensitize those involved
☐ Sought help
☐ Sought religious/spiritual life
☐ Didn’t do anything

116. **Have you ever accessed any of the following services?:**

Multiple responses are possible Read out options

☐ Family protection services
☐ Comprehensive legal services
☐ Psychological services in Care & Treatment Centers
☐ Other. Specify: ……………………………………………………………………………………
☐ None

Social And Economic Support

117. **Which of the following statements describes your work situation before your diagnosis as being HIV-positive?**

☐ Formal work
☐ Informal work
☐ Housework
☐ Studying
☐ Unemployed
☐ Retired
☐ Other……………………………………………………………………………………

118. **Which of the following statements describes your work situation after your diagnosis as being HIV-positive?**

☐ Formal work
☐ Informal work
☐ Self employed
☐ Unemployed, looking for work
☐ Unemployed because of my health
☐ Retired because of my health
☐ Was a student
☐ Continued with my studies
☐ Discontinued with studies
☐ Changed jobs
☐ Other. Specify:……………………………………………………………………………………

119. **Have you accessed some of the following services since disclosing your HIV status?**

Multiple responses are possible Read out options

☐ Health Insurance
☐ Micro-credit
☐ Training
☐ Employment
☐ Scholarship
☐ Food security assistance
☐ Other ……………………………………………………………………………………
☐ None

Empowerment

120. **Do you belong to any civil society/support group/association as a person living with HIV?**

☐ Yes (Specify)……………………………………………………………………………………
☐ No

121. **As a person living with HIV, what activities have you been involved in through this network/these networks?**

Read out options

☐ Meetings
☐ Support Groups
☐ Advocacy
☐ Training
☐ National Fora
☐ Other Specify: ……………………………………………………………………………………

122. **Do you know of any organizations or groups that provide support services to people living with HIV?**

☐ Yes
☐ No Go to question 124

123. **Which kinds of organizations do you know about?**

Multiple responses are possible Read out options

☐ People living with HIV support group
☐ Network of people living with HIV
☐ Non-government organization
☐ Faith-based organization
☐ A human rights organization
☐ Departmental or national AIDS committee or council
☐ International non-governmental organization
☐ UN organization
☐ Other. Specify: ....

124. **In the last 12 months, have you supported other people living with HIV?**

☐ Yes
☐ No Go to question 126

125. **What types of support did you provide?**

Multiple responses possible After respondent answers, probe by asking for any others Do not read out answers

☐ Emotional/ Psychological Support
☐ Economic Support
☐ Referral to other services
☐ Health care support
☐ Company
☐ Physical care
☐ Information support
☐ Spiritual / moral support
☐ Legal support
☐ HIV prevention support
☐ Capacity building
☐ Other ....

126. **Since your diagnosis, how have you been involved in relation to laws and policies that affect people living with HIV?**

Multiple responses possible After respondent answers, probe by asking for any others Do not read out answers

☐ I was consulted
☐ I participated in the development of a law
☐ I was informed
☐ I was part of the validation process of a law
☐ I have never participated in any way

Effectiveness of PLHIV Groups & Organizations

These questions are for respondents who mentioned that they belong to a civil society/community group/association
Check question number 108 to verify

127. **You mentioned that you belong to a network/civil society/support group/association. What type of services and/or activities does the organisation carry out?**

☐ Provides emotional/psychological support
☐ Provides referrals to other services
☐ Provides physical care
☐ Provides information on health
☐ Provides spiritual/moral support
☐ Provides legal support
☐ Provides HIV prevention support
☐ Provides economic support
☐ Capacity building
☐ Helps to foster friendship
☐ Empowerment
☐ Fosters solidarity
☐ I don't know

128. **How important would you say it is to belong to a network of people living with HIV?**

☐ Very Important
☐ Important
☐ Not Important
☐ I Don't know

129. **What do you think should be done to improve the network/civil society/community group/association that you belong to?**

Answer ………

130a. **End Time of Interview- HOUR**

130b. **End Time- MINUTE**

Thank you very much for your time