Rwanda
Biomedical
Centre
Healthy People, Wealthy Nation

Rwanda
People Living with HIV
Index 2.0

Survey Report

2020

Acknowledgements

This report is the summary of findings of survey conducted between October 2019 and June 2020. The period of pandemic covid-19 was a limited factor to meet our initial plans but the joint efforts of different stakeholders should not be unnoticeable. Rwanda Network of People Living with HIV (RRP+) thanks the Government of Rwanda who through the Ministry of Health continues to lead HIV response and particularly the fight against stigma and discrimination among PLHIV in Rwanda. Thanks go to all experts who developed the tool used for stigma and discrimination index (SID) Survey; these include Global Network of People living with HIV (GNP+) , the International Community of Women Living with HIV (ICW), the International Planned Parenthood Federation (IPPF), and United Nations Joint Programme on HIV/AIDS (UNAIDS).

Special thanks to health care providers who facilitated the data collection and the team which lead data collection. The RRP+ acknowledges the effort of its executive secretariat staff led by Mrs. SEMAFARA Sage who worked day and night for smooth implementation of this survey.

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Finally, and importantly, we would like to thank research participants who opened their hearts and provided information about their experiences which will help improve our understanding of stigma and discrimination as part of the AIDS response in Rwanda, the Africa Region and elsewhere.

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Chairperson
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Abbreviations

ART	Antiretroviral Therapy
CoK	City of Kigali
DSDM	Differentiated Service Delivery Model
DRC	Democratic Republic of Congo
FSW	Female Sex Worker
GNP+	Global Network of People Living with HIV
HCP	Healthcare Provider
HIV	Human Immunodeficiency Virus
IPPF	International Planned Parenthood Federation (IPPF),
ICW	International Community of Women
MRC	Medical Research Centre
MSM	Men Having Sex with Men
PE	Peer Educator
PLHIV	People Living with HIV
PPS	Probability Proportional to the Size
UNAIDS	The Joint United Nations Programme for HIV/AIDS
RRP+	Rwanda Network of People Living with HIV
RPHC	Rwanda Population and Housing Census
RBC	Rwanda biomedical Centre
RNEC	Rwanda National Ethics Committee
SDI	Stigma and Discrimination Index
UNAIDS	The United Nations Joint Programme on HIV/AIDS
WHO	World Health Organization

Executive Summary

HIV-related stigma and discrimination is one of the barriers to HIV prevention and management. It limits access to existing and available HIV prevention, care and support services. Available information was of 2009 hence need of up-to-date data to guide intervention and support advocacy efforts. The survey intended to determine the level and document various experience of PLHIV of HIV related stigma and discrimination.

Methodology

Cross-sectionally, we conducted a mixed method of quantitative and qualitative design between October 2019 and June 2020. For the quantitative aspect we planned to give a structured generic questionnaire developed by GNP+ to 938 participants sampled by probability proportional to size of health facilities. The sample included HIV positive people enrolled in care, aged 18 years and above, who provided voluntary consent. For the qualitative component of the study, we conducted six focus groups discussions (FGD) with people living with HIV (PLHIV) who are female sex workers (FSW), men who have sex with men (MSM) and adolescents enrolled into care. In addition, 8 in-depth interviews were conducted with PLHIV who were not enrolled into HIV care of any health facility. The overall PLHIV stigma Index was computed from 96 questions clustered into five indicators to generate a composite indicator. The five clusters were: (1) PLHIV who are concerned about disclosing their status; (2) PLHIV who perceive people fearing to contracting HIV from non-invasive contact; (3) PLHIV who feel judged or blamed for their illness ;(4) PLHIV who think they have experienced stigma in the last year;(5) PLHIV who experience stigma's negative effects on themselves, the family, and the community.

The composite indicators were ranked as very low (Index <15), low (Index 15-29), medium (Index 30-44), high (Index 45-59) and very high (Index ≥60) over a hundred units. We conducted descriptive statistics using STATA version 15. In addition to quantitative part, we summarized the feedback gathered from six Focus group Discussions (FGD) and 8 in-depth interviews.

Findings

The participation rate was 99% (N=950); among respondents, 89% were general PLHIV, 8.5% were FSW and 2.7% were MSM. The participants' socio-economic characteristics showed that 37% were from Kigali City, female predominantly at 72%; the median age was 44 years old (Range: 18-79 years old) and their level of education was primary or less up to 87%. More than 85% of respondents learned about their HIV status in the last 5 years or earlier prior to the survey. With regard to satisfying basics needs, 51% of the respondents reported being unable to meet their basic needs some of the times, while 30% were not able to meet their basic needs most of the time.

Stigma Index

The overall HIV stigma index in Rwanda was very low (Index 15). However, this rate ranking is not homogeneous across the five components that generated the index. All respondents (100%) classified the HIV stigma related to the interaction with health services as very low, the experience of stigma in last twelve months was ranked also as very low by 82%, the concern about disclosing their HIV status was ranked as very low by 63% and internalized Stigma and resilience at 59% was ranked as very low. However only 9.4% classified as very low the stigma related to human rights and effecting change.

The comparison of stigma and discrimination Index (SDI) results in 2009 and 2020, revealed that 80% decrease of SD experience in last 12 months specifically on exclusion from religion activities, social gatherings, family activities, physical harassment or discriminatory gossip. This shows an impressive progress regarding HIV-related SDI. The findings of this survey showed a decrease of more than 50% regarding PLHIV rights abuse, forcing PLHIV to be tested either for insurance, health care, and visa or segregated. Our results show better trend (Index 13) compared to what Kenyan found in 2015 where the index was 45

Participants in FGD reported that the HIV stigma and discrimination considerably reduced over the period in all aspects of life; however, they highlighted stigma still to be a challenge to adolescents living with HIV, and those free from HIV born to HIV parents. Other groups identified to be at high risk of stigma and discrimination were women and key populations. Women because they are blamed to be the source of the infection in the family, and key populations perceived as people with immoral behavior.

Conclusion

The main causes for PLHIV to not enroll into care were internal stigma, religion beliefs, negligence and community stigma. The study revealed the decrease of HIV related stigma and discrimination in Rwanda over the period of 10years. However, the knowledge of PLHIV on laws and policies that protect them was still low. The fear of PLHIV to disclose their status to others was still prevalent among PLHIV especially young people, women and key populations who reported to be at high risk of HIV related SD. Therefore the RRP+ and Rwanda Biomedical Center (RBC) should reinforce psychosocial support to reduce internal stigma, design specific interventions to reduce the SD among adolescents infected and affected by HIV, FSW, MSM and raise awareness of PLHIV on existing laws and policies protecting their rights.

CHAPTER 1. INTRODUCTION

Background and rationale

Despite the existence of human right obligations and policy commitments, HIV-related stigma and discrimination continues to be widespread around the world and in all sectors of society. Following a call from civil society in 2017 to accelerate and scale up action to address stigma and discrimination, UNAIDS, UN Women, the United Nations Development Programme and the Global Network of People Living with HIV (GNP+) agreed to co-convene the Global Partnership to Eliminate All Forms of HIV-Related Stigma and Discrimination and launched the global partnership on 10th December 2018 in Geneva. During the launch the former UNAIDS Executive Director, Mr Michel Sidibé, said "This partnership aims to translate Member States' commitments into well-resourced programs that are proved to work and that can result in the enjoyment of HIV-related rights for all"[1].

HIV related stigma refers to the negative beliefs, feelings and attitudes towards people living with HIV, groups associated with people living with HIV (e.g. the families of people living with HIV) and other key populations at higher risk of HIV infection, such as people who inject drugs, sex workers, men who have sex with men and transgender people[2].

Internal stigma, also referred to as "self-stigmatization", describes the sense of shame that some PLHIV may be induced to feel about being HIV-positive. Internal stigma can lead to low self-esteem, a sense of worthlessness and depression, withdrawal from social and intimate contact, and/or self-exclusion from accessing services and opportunities out of shame[2].

HIV-related discrimination refers to the unfair and unjust treatment (act or omission) of an individual based on his or her real or perceived HIV status. Discrimination in the context of HIV also includes the unfair treatment of other key populations, such as some social contexts, women, sex workers, people who inject drugs, men who have sex with men, transgender people, people in prisons and other closed settings and, in some social contexts, women, young people, migrants, refugees and internally displaced people.

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[1] UNAIDS, Launch of Global Partnership to Eliminate all forms of HIV-related stigma and discrimination,2018

HIV-related discrimination is usually based on stigmatizing attitudes and beliefs about populations, behaviors, practices, sex, illness and death. Discrimination can be institutionalized through existing laws, policies and practices that negatively focus on people living with HIV and marginalized groups, including criminalized populations[2]

HIV related Stigma remains one of the biggest barriers in HIV response as it prevents (PLHIV) from accessing healthcare. A stigma index was developed by and for PLHIV to document and better understand HIV-related stigma experiences faced by PLHIV. The tool was developed by the (GNP+), ICW, IPPF, and UNAIDS. Based on the findings, appropriate interventions are designed to fight against HIV in general and specifically HIV related stigma. [2]

While implementing the PLHIV Stigma Index, PLHIV are at the center of the process as both interviewers and interviewees and drive how the information is collected, analyzed and used - empowering all those involved and strengthening networks of PLHIV[3]. The Stigma Index addresses HIV-related stigma and discrimination, while also advocating on the key barriers and issues perpetuating stigma - a key obstacle to HIV treatment, prevention, care and support.[4]

The PLHIV Stigma Index was globally launched in 2008. Rwanda through its networks of PLHIV including Rwanda Network of PLHIV (RRP+) and Association of Vulnerable Widows Infected and Affected by HIV with UNAIDS' support implemented the first stigma index in 2009 [5]

1.1. Country HIV Context

Rwanda is a small landlocked country located in East-central Africa covering 26.338 square kilometers and sharing borders with four countries, Burundi, Tanzania, Democratic Republic of Congo (DRC) as well as Uganda. The country is divided into four

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[2] The People Living with HIV stigma Index, user Guide 2018

[3] HIV stigma index brief,2017, Updating the People Living with HIV Stigma Index

[4] http://www.stigmaindex.org/accessed on 2nd January 2019

[5] Rwanda Stigma and discrimination survey report,2009

provinces plus the City of Kigali (CoK) and is home to 12 million people as projected by Rwanda Population and Housing Census (RPHC) projections in 2019[6].

HIV prevalence among Rwanda general population has been stable at 3% for the last decade. It is

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[6] Rwanda Population and housing census (RHPC) IV: Population projections,2019

higher among women (3.6%) than men (2.2%); more prevalent in urban (4.8%) compared to rural areas (2.5%). Kigali city remains with the highest prevalence (4.3%) in the country.[7] HIV remains also a burden among Female sex workers (FSW) with 45.8%. It is relatively higher among Men Having Sex with Men (MSM) 4%,[8] compared to the general population. Rwanda is among few countries that have achieved the UNAIDS targets by 2020, with 83.8% of HIV -positive adults aged between 15-64 years old being aware of their HIV-positive status; 97.5% are on ART treatment and 90.1% of them achieving Viral load suppression[7]. Retention of PLHIV twelve months after ART initiation is at 93%[9]. With the launch of Treat All strategy in 2016[10], every person tested HIV is linked and if possible initiated to HIV treatment the same day. When the treatment initiation delays it has to take place within 14 days from testing. This strategy increases ART coverage in the country.

1.2. About RRP+

The Rwanda Network of PLHIV in Rwanda (RRP+) is a civil society organization founded by and for PLHIV in 2003. It serves as a unified voiced umbrella organization of associations/organizations of PLHIV in Rwanda. It coordinates efforts of the PLHIV in responding to HIV and AIDS challenges including addressing HIV related stigma and discrimination.

There is a great importance for having a national body coordinating issues involving PLHIV in the country: the network develops an effective drive in the coordination and management of capacity building, and support for PLHIV in the country.

The following are the objectives of RRP+:

- to participate and support Government efforts in the development of policies and strategies in the HIV response
- to ensure that the power of advocacy for PLHIV is enhanced in all processes of developing policies and different programs in HIV area

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[7] Rwanda Population-Based HIV Impact Assessment ,2019

[8] Behavioral Surveillance Survey (BSS) among Female sex workers and MSM,2015

[9] HIV and viral hepatitis annual report, 2018-2019

[10] Rwanda National HIV guidelines 2016

- to consider and establish ways and means for effective participation of PLHIV and those affected by the pandemic in the activities to contain the spread of HIV in the country
- to ensure that PLHIV in the country have a big stake, duty and responsibility for containing the spread of new infections of HIV.

A decade after the first stigma index survey in Rwanda was implemented, different interventions and activities have been carried out with regard to HIV response and particularly addressing HIV-related stigma and discrimination issue. HIV-related stigma and discrimination situation should not be the same as 10 years back. This is the reason why Rwanda undertook the second stigma index to determine the current level of stigma and the progress so far made by the country. This will also contribute to the global understanding of HIV stigma and its consequences as well as identifying priorities for advocacy.

1.3. Objectives of the survey

1.4.1. Main Objective

The purpose of this survey was assessing the HIV-related stigma and discrimination for supporting advocacy efforts, design appropriate interventions that address the key barriers and issues perpetuating stigma and discrimination.

1.4.2. Specific Objectives

The Stigma Index aimed at:

- Determining levels of HIV related stigma and discrimination among PLHIV in all their diversity, including key populations living with HIV
- Documenting various experiences of HIV-related stigma and discrimination in Rwanda
- Providing an evidence base for advocacy, policy and programmatic interventions to address HIV related stigma and discrimination.

CHAPTER 2. METHODOLOGY

2.1 Study design

This was a cross-sectional survey that used mixed approach: quantitative and qualitative methods. The quantitative component was a three-stage cluster design applying probabilistic selection for general PLHIV and purposive selection for Key Populations enrolled into care. The qualitative aspect used Focus Group Discussions (FGDs).

2.2 Study Population

The PLHIV respondents were sourced at accredited health facilities providing HIV comprehensive care in Rwanda.

Eligibility criteria

Persons who fulfill the requirements were included in the study:

1. A person living with HIV
2. Aged 18 years old and above
3. Mentally and physically able to answer the questions
4. Provided voluntary informed consent

2.3 Quantitative aspect

2.3.1. Sampling Methods

The quantitative aspect was a three-stage cluster design which applied:
(i) Probabilistic selection for general PLHIV and (ii) purposive selection for HIV Key Populations enrolled into a health facility with ART clinics.

The study covered all the four provinces and City of Kigali. Due to financial and time reasons, it was decided that only 2 districts per province be covered. So,

- In the first stage, two districts per province were randomly selected overall 10 districts constituted the sample and represented 1/3 of the total 30 districts of the country.

- In the second stage, based on the average number ART clients, a number of 38 health facilities was estimated to be enough to obtain the sample. In the regards number of health facilities with Anti-retroviral Treatment (ART) clinic [clusters] per district were selected with Probability Proportional to the Size (PPS) of clusters [health facilities providing ART] in a selected district. As HIV Key Population program is not scaled up in all ART clinics, in every selected district with at least one health facility offering key population program, 1 health facility was purposively considered among selected ones.
- Finally, in the third stage, individual PLHIV enrolled into care were selected using random and systematic sampling methods. Randomness was applied for selection of the first participant and the remaining participants were systematically selected at selected health facility.

2.3.2. Sample size

For the general PLHIV on ART, the sample size was calculated based on the following assumptions: (i) p- the overall composite Stigma Index 45.1% [Kenya SDI,2014]; (ii) $\boldsymbol{z}_{\boldsymbol{1}-\frac{\alpha}{2}}$ is the two-tailed Z score, normal value of 0.05=1.96, (iii) Margin of error (d) 5%, (iv) Design effect (Deff) of 2. This procedure yielded a sample size of 761 PLHIV on ART. Adjusting for non-responses rated at 10%, the sample size was rounded up to 837 PLHIV on ART.

Applied Formula

$$= \left(\frac{Z_{1-\frac{\alpha}{2}}}{d}\right)^2 * p(1-p) * Deff$$

- As we did not have any prior information about key populations in regard to Stigma and discrimination Index in Rwanda, the survey purposively and respectively considered 83 Female Sex Workers and 30 Men who have Sex with Men under enrolled in ART clinics.

- The final sample size, including all categories of people for the survey was 950 PLHIV enrolled into care and treatment.

However, after data collection, it was noticed that 938 people all categories of interviewees combined were reached representing a participation rate of 98.7%.

2.3.3. Data collection techniques and tools

The data collection was done by trained PLHIV as recommended in the User guide index 2.0 aiming to enhance full ownership and participation of PLHIV. Prior to the interviews, a two-day training session was organized for data collectors. A pilot data collection was also conducted to test survey instruments and to ensure data collectors have well-understood the process.

Data collection was facility-based and Healthcare Providers (HCP) supported the data collection during the process of selecting eligible participants. Systematic random selection of participants was done ahead of time and selected patients were given an appointment at the health facility. A structured interview was administered to PLHIV who provided informed consent to their participation with the help of the interviewer, providing data for the index. The interviewers recorded information using tablets.

The PLHIV Stigma Index-standard questionnaire 2.0 developed by and for PLHIV through the partnership with GNP+, International Community of Women Living with HIV (ICW), International Parenthood Federation (IPPF) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) was the primary research tool that was used to collect quantitative data from the study respondents to measure HIV- related stigma and discrimination among PLHIV. All participants were asked to respond to HIV related stigma questions based on their experiences mainly in the last 12 months. The questionnaire also included some questions related to stigma and discrimination experience beyond 12 months.

2.4. Qualitative aspect

In addition to quantitative aspect, qualitative information was collected through FGDs. Six FGDs were conducted, two for general PLHIV, 1 for Adolescents living with HIV and included men and women, two for MSM, 1 for FSW. The FGD consisted of between 6 and 8 participants purposively selected. They were held at a health facility or any other identified confidential place. Discussions took approximately an hour to ensure that specific issues related to HIV stigma were covered. Discussions also allowed an open-ended exchange of information among participants who were asked to ‘free list’ the most common HIV related stigma and discrimination practices that happen to them and in the community as well as the most category of people affected by HIV related stigma and discrimination.

2.4.1. Ethical considerations

The Rwanda Stigma Index 2.0 protocol was submitted, reviewed and approved by Rwanda National Ethics committee (RNEC). The committee provided clearance before the survey started. All questionnaires and records from the interviews were stored in a locked file with limited access to RRP+ officials and the consultant. No respondent's names or addresses were recorded to the questionnaire.

2.4 Data analysis

For quantitative data, the analysis was done using statistical software packages (excel, STATA). In the analysis, as the user guide does not provide how to compute the overall Stigma and discrimination Index, we have calculated the Stigma and Discrimination Index as a composite of 5 indicators namely:

1. PLHIV who are concerned about disclosing their status
2. PLHIV who perceive people fearing to contracting HIV from non-invasive contact
3. PLHIV who feel judged or blamed for their illness
4. PLHIV who think they have experienced stigma in the last year
5. PLHIV who experience stigma's negative effects on themselves, the family, and the community.

The idea to compute the indicator so was borrowed from the Kenyan "Stigma and Discrimination 2014". For qualitative data, field notes were used to capture relevant information from members of FGDs, similar statements from participants were grouped and compiled together to provide information on HIV related stigma and discrimination.

CHAPTER 3. RESULTS

This report describes the findings following the analysis of data collected using the Stigma Index 2.0 and borrowed composite indicator from Kenya

SECTION I: FINDINGS FROM QUANTITATIVE COMPONENT

3.1. SOCIO-DEMOGRAPHIC CHARACTERISTICS

This section presents general background information about PLHIV involved in the survey. A total of 938 participants out of 950 expected were interviewed. Participation rate was at 98.7%. The respondents were grouped into three categories: (i) General PLHIV, (ii) Female Sex Workers and (iii) Men Having Sex with Men (MSM).

Table 1. Number of respondents per population category

SN	Population	N	%
1	General PLHIV	832	88.7
2	FSWs	80	8.5
3	MSM	26	2.8
Total		**938**	**100.0**

Among 938 respondents 832 were general PLHIV, 80 Female Sex Workers living with HIV and 26 MSM living with HIV.

Table 1 outlines respondents' sociodemographic characteristics including residence, age, and education level and employment status. Most of respondents attend health facilities from Kigali city (37.4%). The current data from HMIS reveal that 45% of PLHIV country wide attend HIV clinics in Kigali[11]. The mean and median age is 44 years. The majority of the respondents were aged between 35-44 years old while women respondents (72.4%) were thrice as many as men (27.6%). Respondents' education levels were generally low with more than 3/4 reporting no formal education or primary education (22.4% and 65% respectively). Only 0.9% reported to have university education. For employment status, ¼ of respondents were unemployed.

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[11] Rwanda HMIS, report 2020

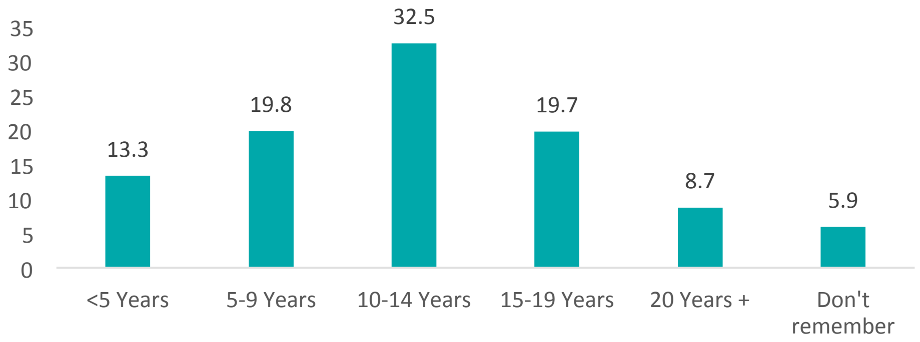
Table 2. Socio-demographic characteristics

Categories	**Number**	**%**
Overall	**938**	**100.0**
Province of Residence		
East	150	16.0
Kigali	351	37.4
North	177	18.9
South	74	7.9
West	186	19.8
Age group		
18-24	37	3.9
25-34	181	19.3
35-44	267	28.5
45-54	278	29.6
55+	175	18.7
Sex		
Female	679	72.4
Male	259	27.6
Currently in an intimate/sexual relationship		
Yes	420	44.8
No	518	55.2
Education level completed		
No formal education	210	22.4
Primary school	610	65.0
Secondary and Technical school	110	11.7
University education	8	0.9
Current occupation		
In full-time work (as an employee)	26	2.8
In part-time work (as an employee)	294	31.3
Working full-time, but not as an employee (self-employed or business owner)	236	25.2

Doing casual or part-time work (self-employed or paid work for others)	149	15.9
Unemployed and not working at all	228	24.3
Student	5	0.5

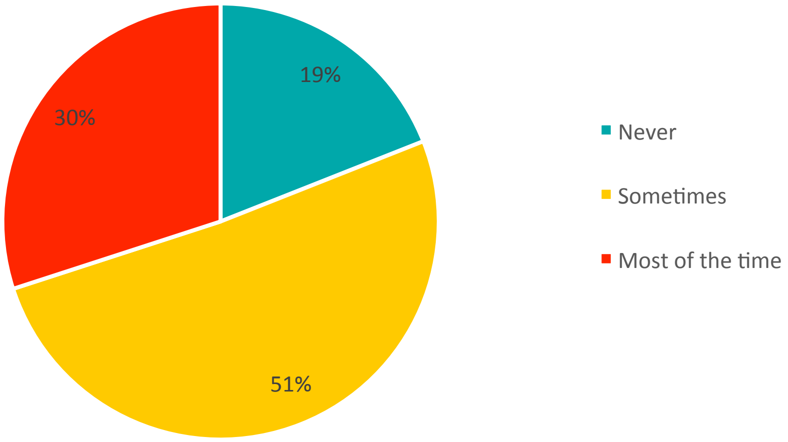
Figure 2 shows that 32.5% of respondents knew their HIV status for between 10-14years at the time of the interview. Only 13.3% knew their HIV status for a period of less than 5years. The overall figure shows that more than half of the respondents had been living with HIV for more than 10years.

Figure 1. Time after knowledge of HIV status



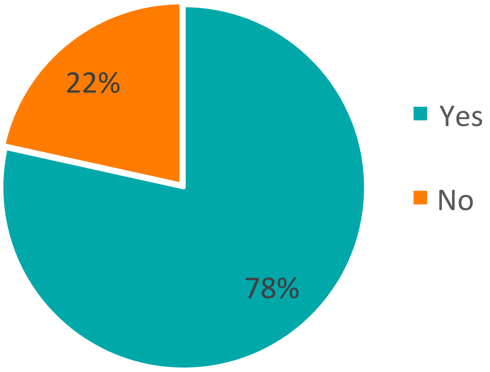
During the data collection, respondents were asked how often they had been unable to meet their basic needs for 12 months period prior to the interviews. It was noticed that 19% of the respondents had never failed to meet their basic needs while half of the respondents (51%) faced the issue sometimes and 30% were unable to meet their basic needs most of the time.

Figure 2.Percentage of respondents who have been unable to meet their basic needs in the last 12 months



78% of respondents confirmed to be a member of a network or a group of people living with HIV. This can partly be attributed to the existence of RRP+ which brings together more than 90,000 PLHIV countrywide gathered in associations. There is also a Differentiated Service Delivery Model(DSDM) adopted by the Ministry of Health from 2016, whereby all PLHIV enrolled at health facilities are encouraged to adhere to PLHIV support group, where they meet on monthly basis in their villages[12].

Figure 3. Belonging to a network or support group of people living with HIV



3.2. DESCRIPTION OF 5 COMPONENTS OF COMPOSITE INDICATOR

3.2.1. Stigma related to human rights and effecting change

The breakdown of questions and statement in above mentioned component showed that the violation of human rights was very low in Rwanda as the percentage of respondents in last 12 months or before who have been forced to get test for HIV for any reason or arrested, detained because their HIV status or forced to have sex was consistently below 1% (See the table below).

Table 3. PLHIV rights abuse

PLHIV right abuse	**No (%)**	**Yes in**	**Yes but**

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[12] MOH-RBC, HIV national guidelines, edition 2016

		last 12 months (%)	**not in last 12 months (%)**
I was forced to get tested for HIV or disclose my status in order to obtain a visa or to apply for residency or citizenship in a country	99.5	0.1	0.4
I was forced to get tested for HIV or disclose my status in order to apply for a job or get a pension plan	99.0	0.6	0.3
I was forced to get tested for HIV or disclose my status in order to attend an educational institution or get a scholarship	99.2	No data	0.4
I was forced to get tested for HIV or disclose my status in order to get healthcare	97.9	0.2	0.7
I was forced to get tested for HIV or disclose my status in order to get insurance	97.1	0.2	0.0
I was arrested or taken to court on a charge related to my HIV status	97.3	0.8	0.4
I was detained, quarantined, isolated or segregated because of my HIV status	97.6	1.1	0.3
I was denied a visa or permission to enter another country because of my HIV status	90.6	No data	NA
I was denied residency or permission to stay in another country because of my HIV status	91.7	0.1	0.0
I was forced to disclose my HIV status publicly or my status was publicly disclosed without my consent	98.6	0.5	0.8
I was forced to have sex when I did not want to	98.6	0.9	0.5
Effecting Change	**No**	**Yes**	
Do you know if there are any laws in the country to protect people living with HIV from discrimination?	55.0	45.0	NA
Challenged or educated someone who was engaging in stigma or discrimination against you	69.7	30.3	NA
Have you Challenged or educated someone who was	65.1	34.9	NA

engaging in stigma or discrimination against other people living with HIV			
Have you Provided emotional, financial, or other support to help someone living with HIV deal with stigma and or discrimination	75.4	24.6	NA
Have you Participated in an organization or educational campaign working to address stigma and discrimination against people living with HIV	70.0	30.0	NA
Have you encouraged a local leader or a politician to take action about issues of stigma and discrimination against people living with HIV	81.6	18.4	NA
Spoke to the media about issues of stigma and discrimination against people living with HIV	96.4	3.6	NA

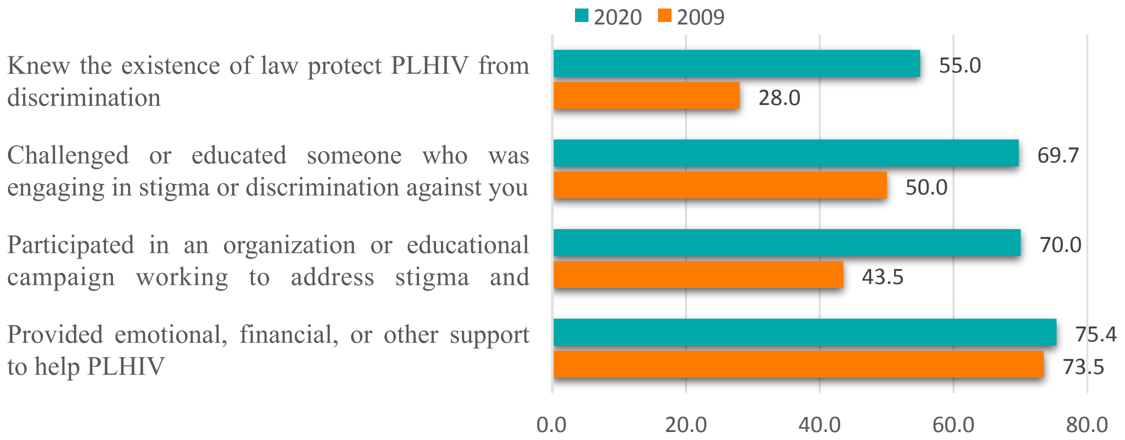
3.2.1.1. The comparison of effecting change of 2009 and 2020

There was an increase in four variables collected in 2009 and 2020. The increase concerned

- Awareness of PLHIV on the existence of laws that protect them from discrimination. It increased from 28% in 2009 to 55% in 2020.
- PLHIV who challenged or educated someone who was engaged in the stigma and discrimination increased from 50% to 70% in 2009 and 2020 respectively
- PLHIV who participated in organizational or educational campaign working to address the stigma and discrimination were 43% in 2009 and 70% in 2020.

A minor improvement was observed in peer supporting financially, emotionally.

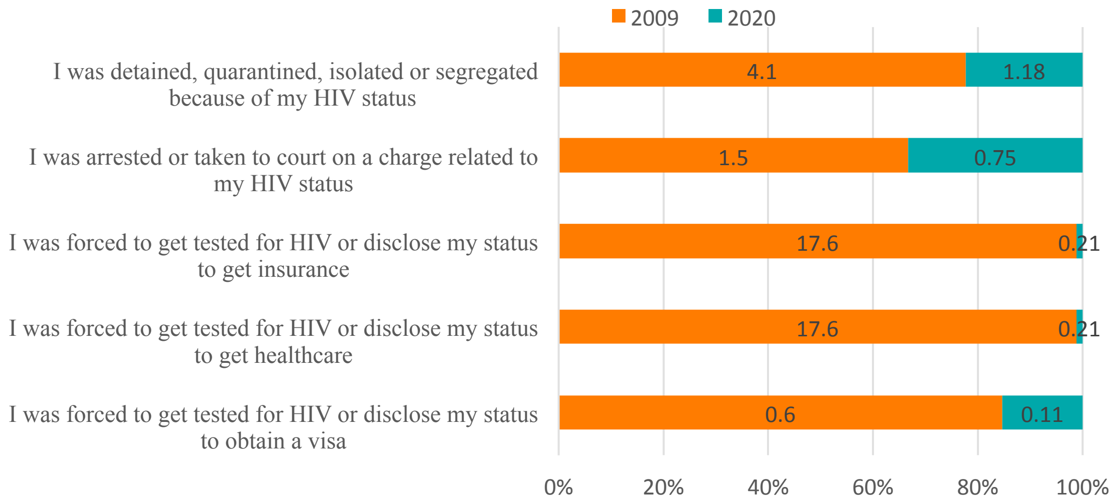
Figure 4. The comparison of effecting change of 2009 and 2020 (%)



3.2.1.2. *Comparison of PLHIV rights abuse in 2009 vs 2020*

PLHIV rights abuse has reduced more than half in 2020. This mainly concerns forcing PLHIV to be tested either for insurance, health care, and visa or segregated.

Figure 5. The comparison of PLHIV rights abuse in 2009 and 2020



3.2.2. PLHIV who self-reported experiencing the stigma and discrimination in last 12 months

Among the respondents 21.5% (N=938) had been verbally harassed in the last 12 months prior to the interview due to their HIV status. 11.7% revealed that they were aware of other people than family members made discrimination against them in the last 12 months while 5% have been excluded from family activities and 5.8% discriminated by their own families. However, stigma and discrimination related to social gatherings is still there but at low rating (4.8%), excluded from religious activities (0.7%). (See the table below)

Table 4. Proportion of PLHIV victim of stigma experience in last 12 months by different forms

Question	**No**	**Yes, within the last 12 months**	**Yes, but not in the last 12 months**
Has someone ever verbally harassed you?	57.8	21.5	20.7
Ever been aware of other people (other than family members making discriminatory	75.5	11.7	12.8
Has someone ever blackmailed you because of your HIV status?	86.7	7.9	5.4
Have you ever been aware of family members making discriminatory remarks or gossip	85.4	5.8	8.8
Have you ever been excluded from family activities?	84.9	5.2	9.9
Have ever been excluded from social gatherings or activities	86.2	4.8	9.0
Ever been refused employment or lost a source of income or job because of your HIV status?	90.4	4.8	4.8
Has someone ever physically harassed or hurt you?	92.6	3.8	3.5
Have you ever been excluded from religious activities or places of worship?	97.8	0.7	1.5
Has your job description or the nature of your job ever changed, because of your HIV status?	98.4	0.5	1.1

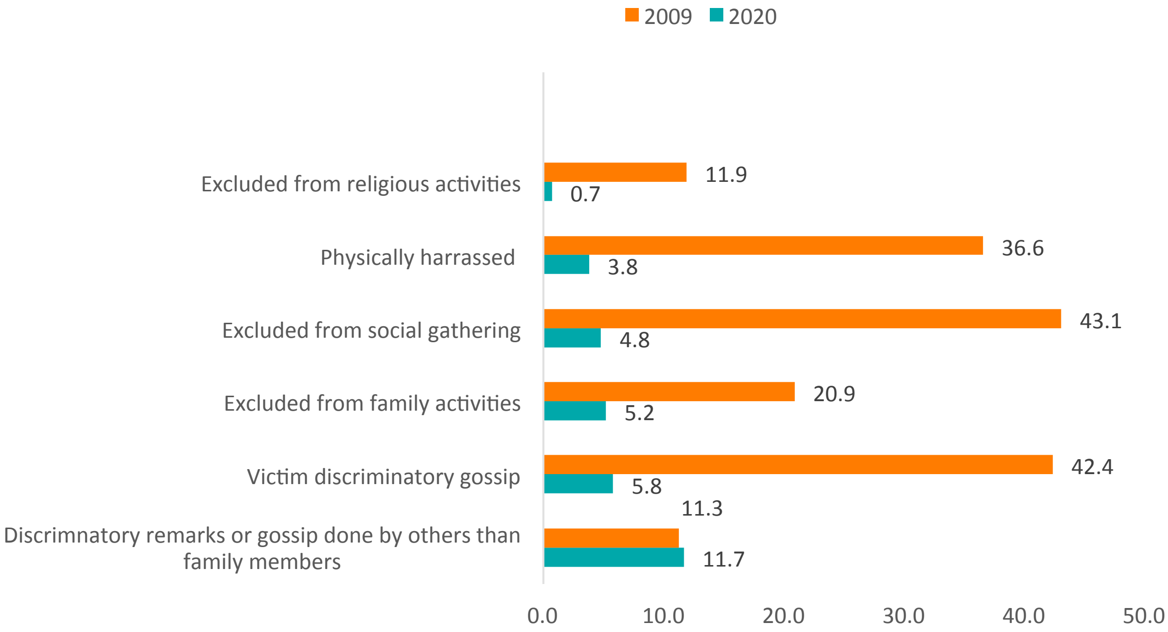
All categories of people living with HIV faced stigma and discrimination at different levels. However, it is noticed that some categories of PLHIV experience on average more stigma:

- Young people aged between 25-34 years (48%) during the last 12 months prior to the survey;
- More women than men faced stigma: 34.8% of sampled women vs 22.4% of sampled men
- Key populations (FSW 57.5% vs MSM 50%)

3.2.2.1. Comparison of PLHIV who experienced the stigma and discrimination in 12 months

Exclusion of PLHIV from religion activities, social gatherings, family activities as well as physical harassment and discriminatory gossip have generally reduced at 80% in 2020. However, the respondents who have been aware of discriminatory remarks or gossip from others than their family members remained the same or slightly increased.

Figure 6. Comparison of Proportions of respondent's victims of stigma and discrimination in 12 months prior to interview



3.2.2.2. Stigma experiences by characteristics

All age categories of people living with HIV faced stigma and discrimination. However among the respondents who experienced any form of stigma and discrimination more than others during the last 12 months prior to the survey were:

- Those aged between 18-34 years old compared to other age categories
- Women compared to men 34.8% vs 22.4%
- Key populations (FSW 57.5% vs MSM 50%)

Table 5. Proportion of participants with any form of Stigma experiences by characteristics

Category	No		Yes		Total
	N	%	N	%	N
Total	644	68.7	294	31.3	938
Age group					
18-24	27	73	10	27	37
25-34	94	51.9	87	48.1	181
35-44	176	65.9	91	34.1	267
45-54	347	76.6	106	23.4	453
Sex					
Female	443	65.2	236	34.8	679
Male	201	77.6	58	22.4	259
Currently in Union					
Yes	314	74.8	106	25.2	420
No	330	63.7	188	36.3	518
Highest level of formal education completed?					
No formal education	141	67.1	69	32.9	210
Primary	409	67.0	201	33.0	610
Secondary and University	94	79.7	24	20.3	118
Current occupation					
In full-time work (as an employee)	20	76.9	6	23.1	26
In part-time work (as an employee)	194	66	100	34	294
Working full-time, as a self-employed or business owner	170	72	66	28	236
Doing casual or part-time work	105	70.5	44	29.5	149
Unemployed	155	66.5	78	33.5	233
Province					
East	101	67.3	49	32.7	150
Kigali	239	68.1	112	31.9	351
North	135	76.3	42	23.7	177
South	49	66.2	25	33.8	74
West	120	64.5	66	35.5	186
Member of a network or support group of people living with HIV?					
Yes	507	68.9	229	31.1	736
No	137	67.8	65	32.2	202
Participant category					
General PLHIV	597	71.8	235	28.2	832
Female sex workers [FSWs]	34	42.5	46	57.5	80
Men who have sex with men [MSM]	13	50	13	50	26
How long (in years) have you known your HIV-positive status?					
<5	84	67.2	41	32.8	125
5-9	123	66.1	63	33.9	186
10-14	213	69.8	92	30.2	305
15-19	134	72.4	51	27.6	185
20+	54	65.9	28	34.1	82
Don't remember	36	65.5	19	34.5	55

3.2.3. Internalized stigma and resilience

3.2.3.1. Perception and fear caused by HIV status

The table below shows perceptions and fear respondents had as a result of their HIV-positive status. Questions were asked whether the respondent felt ashamed, guilty, blamed themselves, had low self-esteem. The results showed that around 40% of respondents had difficult of telling people about their HIV infection, 33% hiding their

HIV status to others, 33% feeling dirty, 24% felt guilty, 23% felt ashamed and 20% felt worthless because they were HIV positive. (See table below)

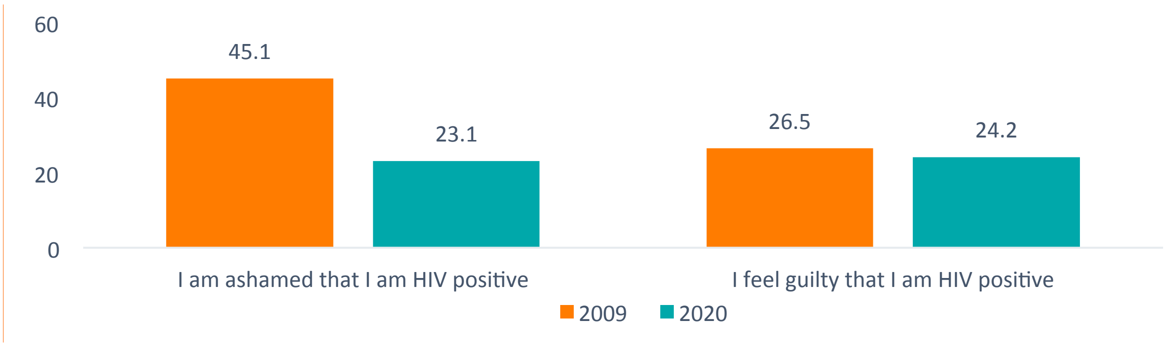
Table 6.Feelings and fear caused by HIV status among respondents

	Disagree	**Agree**
It is difficult to tell people about my HIV infection	60.3	39.7
I hide my HIV status from others	66.5	33.5
Being HIV positive makes me feel dirty	67.3	32.7
I feel guilty that I am HIV positive	75.8	24.2
I am ashamed that I am HIV positive	76.9	23.1
I sometimes feel worthless because I am HIV positive	79.9	20.1

3.2.3.2. Comparison of internal stigma in 2009 and 2020 for feelings and fear

Comparison of findings of 2009 and the current data are not fully comparable due the adaptation of the SDI questionnaire. However, feeling ashamed or guilty due to HIV status reduced in 2020 compared to 2009. Feeling guilty decreased from 26% in 2009 to 24% in 2020, while feeling ashamed decreased in 2009 from 45% to 23% in 2020. (See graph below)

Figure 7.The proportion comparison of PLHIV ashamed and guilt of their HIV status in 2009 and 2020



3.2.3.3. Decisions not to engage in some activities because of HIV status

The survey assessed the proportion of PLHIV who took decisions to not engage in some activities because of their HIV status within 12 months prior to data collection. Findings reveal that most common activity affected was having sex,

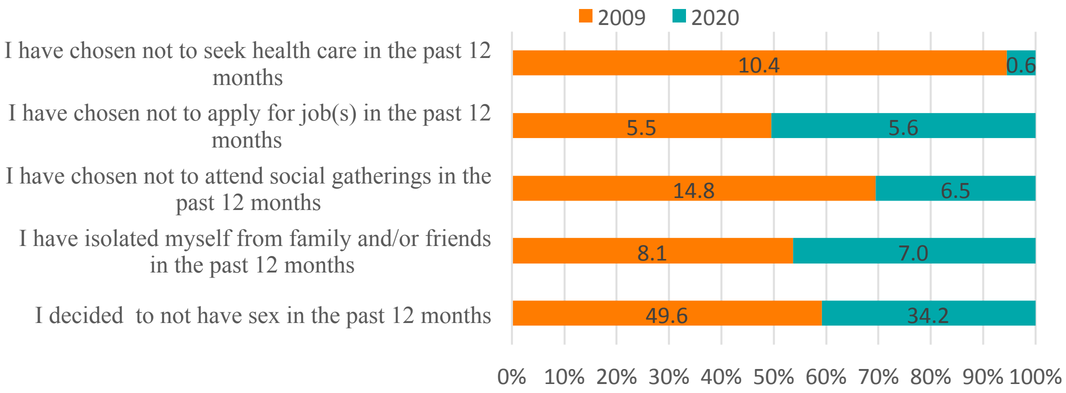
Table 7.Decision not to engage in some activities because of HIV status (N=938)

	No	Yes
I decided to not have sex in the past 12 months	65.8	34.2
I have isolated myself from family and/or friends in the past 12 months	93.0	7.0
I have chosen not to attend social gatherings in the past 12 months	93.5	6.5
I have chosen not to apply for job(s) in the past 12 months	94.4	5.6
I have chosen not to seek social support in the past 12 months	95.4	4.6
I have chosen not to seek health care in the past 12 months	99.4	0.6

3.2.3.4. Comparison of level of decisions not to engage in some activities in 2009 and 2020

The decision of not seeking the health care in 12 months prior to data collection highly reduced from 10.4% to 0.6% in 2020, and results showed that PLHIV who decided not attending the social gatherings reduced more than a half in 2020(6.5%)compared to 14.8% in 2009 (See graph below)

Figure 8.Comparison of level of decisions not to engage in some activities in 2009 and 2020



3.2.3.5. Desire, ability and self-confidence affected or not by HIV status among PLHIV

The desire to have children was negatively affected by their knowledge of their HIV status for 30.9% of the respondents and personal goals or achievements affected negatively for 25.8% of them. The ability to cope with stress, to find love, to practice religion, contribute to community and other have been negatively affected within 12 months prior to data collection. However this section was not included in 2009 which does not allow comparison with the stigma index results of 2009

Table 8. Impact of HIV status to desire, ability and self-confidence among PLHIV (N=938)

	Positively affected by my status	**Not affected**	**Negatively affected**
My desire to have children over the past 12 months has been:	15.8	8.1	30.9
My achievement of my personal or professional goals	54.2	20	25.8
My ability to cope with stress over the past 12 months:	55.7	24.9	19.4
My ability to find love over the past 12 months has been:	60.1	22	17.8
My ability to practice a religion faith as I want to has been:	70.9	14.5	14.6
My ability to contribute to my community has been:	68	21.7	10.2
My self-confidence over the past 12 months:	83.1	8.8	8.1
My ability to have close and secure relationships with others	83.7	13	3.2
My self-respect over the past 12 months:	89.1	8.6	2.4
My ability to respect others over the past 12 months:	88.5	10.1	1.4

3.2.4. PLHIV concerned about disclosing their HIV status

Disclosing their HIV status to non-health professionals had been difficult for the last decade. However, respondents reported that disclosing their HIV status made them free and capable to cope with the infection. The computation of 15 questions related to HIV disclosure scored very low (3.0).

Table 9. Concerns about HIV status disclosure (N=938)

Was your HIV status?	**NO**	**YES**
Ever disclosed to your neighbours without your consent	80.8	19.2
Ever disclosed to Other family members without your consent	84.3	15.7
Ever disclosed to your husband/wife/partners without your consent	85.9	14.1
Ever disclosed to your friends without your consent	86.5	13.5
Ever disclosed to your Community leaders without your consent	88.9	11.1
Ever disclosed to your children without your consent	90.7	9.3
Ever disclosed to your co-workers without your consent	98.2	1.8
Ever disclosed to your employer without your consent	99.3	0.7

3.2.3.6. Comparison between 2009 and 2020 on disclosing the status of PLHIV without their consent

Though the score of disclosing HIV results without consent of PLHIV was classified as very low in 2020, the results doubled what found in 2009 for many related questions. This included disclosing HIV status without PLHIV consent to neighbors, family member, husband or wife, friends, community leaders, children even though the stigma in general reduced. The hypothesis of this discrepancy of stigma reduction and the increase of disclosure without consent can be linked to duration of PLHIV on ART. Most of PLHIV have been enrolled into care 10 years ago. They are used to attend often HFs and meet their peers either at HF or in support groups since HIV services were decentralized to health centers which was not the case in 2009. Positive discrimination at community level can also be one of the reasons, where PLHIV could be selected for some benefits, for instance schools fees for their children, income generating activities dedicated for PLHIV. However further investigations could be adding value to this analysis.

Table 10. Comparison between 2009 and 2020 on disclosing the status of PLHIV without their consent (N=938)

Was your HIV status?	**2020**	**2009**
Ever disclosed to your neighbours without your consent	19.2	8.7
Ever disclosed to Other family members without your consent	15.7	4.1
Ever disclosed to your husband/wife/partners without your consent	14.1	1.8
Ever disclosed to your friends without your consent	13.5	8.7
Ever disclosed to your Community leaders without your consent	11.1	4
Ever disclosed to your children without your consent	9.3	4.1
Ever disclosed to your co-workers without your consent	1.8	3.8
Ever disclosed to your employer without your consent	0.7	2.6

3.2.5. Interaction with healthcare services

PLHIV interact with the healthcare providers more often as they go to health facilities for clinical visit and/or pharmacy refill. This section describes experiences of PLHIV for HIV-specific healthcare and non-HIV related health needs.

Table 11.Interaction with health services

Questions	N=938	%
In the past 12 months, when seeking HIV-specific health care, have you experienced any of the following from health facility staff working in the place you receive your HIV care? (N=938)		
Denial of health services because of your HIV status	11	1.2
Being advised not to have sex because of your HIV status	55	5.9
Being talked badly about or gossiped about because of your HIV status	13	1.4
Verbal abuse (yelling, scolding, or name calling or being otherwise verbally abused)	10	1.1
Physical abuse (pushing, hitting, or being otherwise physically abusive) because of your HIV status	2	0.2
Avoidance of physical contact with you	12	1.3
Telling other people about your HIV status without your consent	9	1.0
In the past 12 months, when seeking care for non-HIV related health needs, have you experienced any of the following treatment by health facility staff?		
Denial of health services because of your HIV status	1	0.1
Denial of dental care because of your HIV status	1	0.1
Being advised not to have sex because of your HIV status	18	1.9
Being talked badly about or gossiped about because of your HIV status	3	0.3
Verbal abuse (yelling, scolding, or name calling or being otherwise verbally abused	0	0.0
Physical abuse (pushing, hitting, or being otherwise physically abusive) because	1	0.1
Avoidance of physical contact with you/taking extra precautions (such as wearing double gloves…)	4	0.4
Telling other people about your HIV status without your consent	5	0.5
In the last 12 months, has a healthcare professional done any of the following, SOLELY BECAUSE OF YOUR HIV STATUS?		

Advised you not to mother/father a child	58	6.2
Pressured or incentivized you to get sterilized (a surgical procedure to prevent you from having children; for example, a vasectomy or tubal ligation)	3	0.3
Sterilized you without your knowledge or consent	1	0.1
Denied you contraception family planning services	1	0.1
Told you that in order to get your HIV (antiretroviral) treatment you had to use contraception, or a specific method of contraception	7	0.7
Advised you to terminate a pregnancy	0	0.0
Pressured you to use a specific type of contraceptive method rather than counseling you on a range of available options	12	1.3
Pressured you to use a particular method of giving birth delivery option	3	0.3
Pressured you to use a particular infant feeding practice	4	0.4

The behavior and advises from the healthcare providers seems very much appropriate except for the following issues:

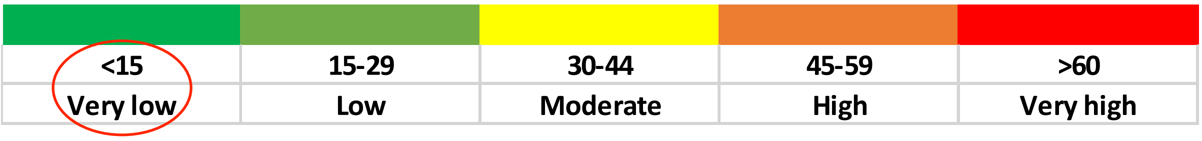
- 5.6% of respondents have been advised in the last 12 months prior to the survey by health care workers not to have sex because of their HIV status
- 6.2% have been advised in the last 12 months not to mother or father a child

The findings on sexual and reproductive health among PLHIV need deep analysis as the law in Rwanda prohibit any medical action without consent of beneficiary. However, some studies showed that beneficiaries of sterilization methods might regret after, hence blaming health care providers and in addition to that, the knowledge of participants to differentiate the sterilization and long term method was observed to the case who reported being sterilized without consent but also reported given another method after; he/she explained in following word “I told the story to the supervisor of my health care provider and he decided to change the method” See the dataset.

3.3. STIGMA INDEX-COMPOSITE INDICATOR

The Composite SDI used 96 questions clustered into 5 categories of indicators. The index was estimated on a scale of 1-100. Each category was equal to 20 units. The cumulative scores were then averaged to yield an overall stigma score. The extent to which PLHIV in Rwanda demonstrate stigma in each category was rated according to the score of each category. Indicators used for the SDI were each scored on a 100-point scale. Based on their overall scores, individual categories of SDI were then calculated and rated on a scale of 1 to 100.

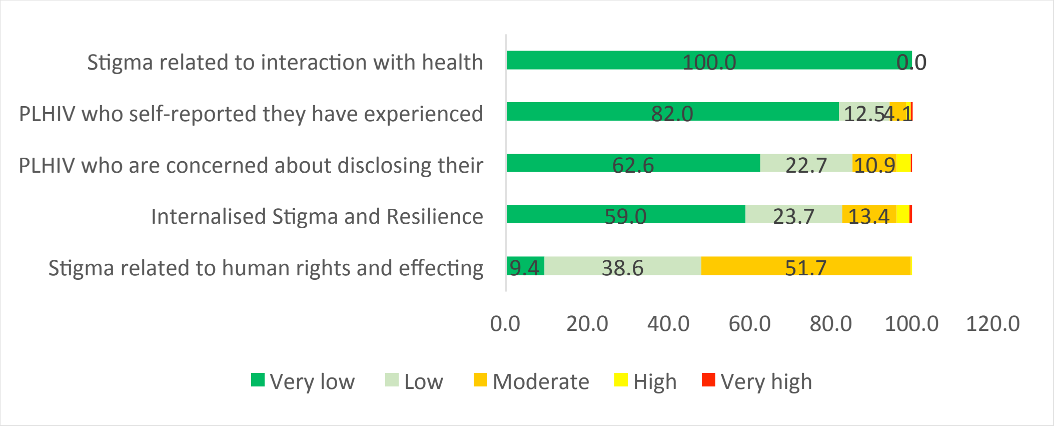
Figure 9.Stigma and Discrimination rating



🟩	🟩	🟨	🟧	🟥
<15	**15-29**	**30-44**	**45-59**	**>60**
Very low	**Low**	**Moderate**	**High**	**Very high**

The SDI rating was ranked as very low based on score over 100 (Score Index 13.2). The classification was not homogeneous within five components we used to compute the index for their ranking was very low at 100% on stigma related to health services, 82% for experiencing the stigma and discrimination, 63% on stigma and discrimination related to disclosure their status, 59% on internal stigma and resilience but only 9% for stigma and discrimination related to human right and effecting change (See the graph below). The ranking of moderate, high or very high were almost absent to stigma and discrimination related to health service and only 4% ranked as moderate on people who experienced the stigma within last 12 months, therefore to sustain the achievements was recommended but internal stigma and resilience, disclosure of HIV status and human right and effecting change were in need of improvement.

Figure 10. Stigma and discrimination rating



SECTION II: FINDINGS FROM QUALITATIVE COMPONENT

3.4.1. FGD with PLHIV enrolled into care

The results have been presented by the flowing themes;

- Understanding on HIV stigma and discrimination
- The existence of HIV stigma and discrimination
- Most PLHIV affected by stigma

Theme 1: Understanding on HIV stigma and discrimination

Most of MSM who participated in the FGDs understand the meaning of HIV-related Stigma and Discrimination as shown in the following testimonies:
"For me, I understand discrimination as unjust treatment of someone based on the fact that I am HIV positive. People who discriminate PLHIV think that when you are HIV positive, you are finished, you are about to die." -Said the MSM living in Kigali City.

.Stigma and Discrimination with regards to HIV/AIDS is like when you're a member of microfinance group (IKIMINA) but you're not trustworthy to a point you cannot borrow some amount of money like any other member just by the assumption that tomorrow or after tomorrow you'll die or you may not be able to repay and you cannot be elected as one of group leader.

You know, at times a non-HIV person who used to Stigmatize PLHIV and thereafter happens to get tested HIV Positive; as a result, this one keeps away from others so they won't know has been infected. Such a person chooses to discriminate from others and it's an indication of auto-stigma.

Theme 2: The existence of HIV stigma and discrimination

The stigma and discrimination is still there mainly work-related, there are some services you cannot afford when you're HIV positive. For instance restaurant, military, police and housekeeping services e. I have been victim of HIV stigma when I went to Kigali for job seeking (housekeeper). I brought the transfer from health facility and asked my Boss (wife) where I could get care, she said she cannot employ an HIV positive person, good enough she gave me the transport fees and sent me back" –

"I remember some years ago, a pastor brought an idea to put a sign(red ribbon) on PLHIV faces, as strategy to identify easily PLHIV and avoid them and consequently break HIV transmission. Nowadays , no one can say that,I as we have an umbrella of religious"Rwanda Interfaith Council on health" that is currently involved in fight against HIV related stigma You can be appointed for any activity in churches regardless your HIV status" -Said FSW

"Compared to the previous years, HIV related stigma and discrimination has been decreasing considerably. I can testify this personally. I knew that I have HIV since 2003; at that time, I was stigmatized a lot such that even some of my friends left me and when I tried to ask them, if I could to pay them visit, but they always found excuses . As of today, some of them have come back to me and apologized; we can now share all things because they understand the modes of HIV transmission and prevention. They can lend me money while at that time they could'nt as they were expecting me to die the following day.. I am happy that HIV stigma and discrimination is decreasing; it is a great step. I take this occasion to thank all those who participated in that fight; it was a fight!"-Reported an MSM in Kigali City.

Another MSM added that *"The stigma and discrimination towards PLHIV is decreasing though there are still some few people, especially the elderly ones, who still think that PLHIV are not like others. We hope that, by time, they will change their mentality too. The HIV infection is no longer a strange disease, rather a disease like others. People are no longer scared of us."*
In regard to the reason why PLHIV were still experiencing stigma and discrimination, the participants revealed the following:

"From my point of view, those who are still discriminating PLHIV do not understand how HIV is transmitted; do not know that there are drugs to treat related opportunistic infections; do not understand the difference between HIV and AIDS; do not know that PLHIV who adhere to the HIV treatment can do the works that others can do, that PLHIV can live longer…. For me, they have poor knowledge on HIV/AIDS. Please, teach them…."- Expressed the MSM participant in Kigali City.

Within a FGD for General PLHIV most of participants said "Yes". As proof there is "stigma and discrimination when ones' status is disclosed to others and gossiped about. Friendship or intermarriage between HIV and non-infected still suffers stigma and discrimination": quoting Participant 7&2. In addition, PLHIV seeking HIV services far from their Home ("usually called Diaspora") are likely to be stigmatized or auto-stigmatized just because they spend transport cost and time while they can get the services nearby their homes (Participant6).

There is a lot stigma and discrimination among so called "Intellectuals"-most of these people we don't see them in our public health facilities and even if they go to private facilities, the cost is high like the viral load test is 50,000RWF which is not affordable to everyone. So, we wonder why they don't seek care in the public health facilities (Participant 4).The form of stigma and discrimination most prevalent is gossiping for generally, PLHIV are considered the same as others in Rwanda (community and or at workplaces, receive same quality services as others) except individuals who may treat PLHIV in their own ways.

Theme 3: Most PLHIV affected by stigma

Young People

Although HIV related stigma and discrimination is decreasing, we asked the participants about the categories of PLHIV experiencing more stigma and discrimination than others. The participants revealed that the young PLHIV and populations at high risk of HIV infection continue to face the "little" stigma and discrimination. The quotes below show the categories of PLHIV who experience stigma and discrimination.

> *"I knew that I am HIV positive when I was 12 years old, now I am 25 years old. It was not easy to me to understand how HIV chose me among other siblings. My adherence was so bad and consequently I failed the first line.*
> *When I attended adolescents' support group I got comfort and started my HIV status. However, the stigma among adolescents and youth may be higher because this is a sexually active group and everyone who knows my status and sees me chatting with a boy looks me in lenses of infecting that boy.*
> *Especially for HIV girls when you disclose your status to a boy who is dating you, the girl is at high risk of being stigmatized by the boy but also the boy may disclose your status to others in the context of preventing HIV transmission to the community. My advice to HIV adolescents and youth is to be open and disclose their status so that none will be gossiping their status as hot news. HIV Adolescent*

> *"It seems to me that the youth living with HIV, especially young girls, are most affected by stigma and discrimination. People tend to think that they are potentially infecting others. Let me explain my idea: For instance, if it is a young girl, when people see her, they say that she is going to infect young boys and men. Based on this belief they always try discriminating her. On this, I know a case of young girl who was fired from her work in a certain Hotel because she was HIV positive. Her boss told her that given that she is still young, there are many clients who may ask her to sleep with them and there is a risk to infect them."*

"In a family where one or both parents live with HIV, this status affects also the children (young people) especially boys and girls who are preparing to get married. Though a boy or a girl is not infected but the community tends to associate the parent status with the whole

family and fear to be engaged in marriage with a boy or a girl coming from a family with a history of HIV". It becomes worse when a young person is known as HIV+ in the community and is seeking a partner for marriage. Once in love, a discordant boy or girl friend breaks-up the relation once they disclose that they are HIV+. It goes even further as it may affect young relatives, because of the only one relative living with HIV. People fear that your husband or your wife will infect you".

This discriminates young people living with HIV and it brings them to start searching/seeking their peers, those who share the same HIV status for relationship which is definitely not easy for them. Consequently, young people do not see their future and tend to stigmatize also themselves and lose confidence. They tend to hide their status due to that stigma and might end by infecting others as they don't want any other person to know their status".Reported PLHIV from Kirehe

Women

"Another group of people living with HIV affected by Stigma and discrimination, are Women.

They are the backbone of a family and face many challenges related to HIV stigma and discrimination. When they are HIV+ in a concordant couple, men tend to designate to them as the ones who brought the infection to the family and they face violence in different ways. If the husband dies before the woman, the family in-laws harassed the woman and her rights are violated since she cannot keep for example their properties (e.g.: land, houses…), though she is protected by the law, but culture has also its own influence. When a woman is infected and living in a discordant relationship, its worse. She is accused of bringing a curse to the family, she is judged as a prostitute, willing to kill the husband and can even be chased from the family in law. When the man is the only one infected in the family, they are also victims of violence when it comes to sexual intercourse because men do not want to use condom for protection"

Key populations

My impression is that people who discriminate us (PLHIV) tend to link our HIV status with -immoral behavior. They think that it is the punishment for our bad behaviors. "In addition to being PLHIV we also face a stigma as MSM -MSM participant reported.

. "To add to my peer's idea, I know some cases of stigma and discrimination, but they all go to Lesbian, Gay and female sex workers. Myself I am a MSM and guess this is because their practices are not culturally and spiritually accepted in our society! People think that this it was us who brought us those problems. We are labelled as HIV carriers. We face double stigma, being a key pop at the same time having HIV. We are blamed to be responsible our status-People say we deserve to be HIV positive"

3.4.2. In-depth interviews with PLHIV not enrolled into care.

In addition to both qualitative and quantitative collected data from PLHV enrolled , the TWG advised also to try to reach PLHIV who are not enrolled into care and get their opinions in relation to HIV related stigma and discrimination. Peer educators supported in identifying PLHIV not attending health facilities for their treatment. Among 23 PLHIV identified, only 8 accepted to meet for in-depth interview

Table 12.Summarized reason and characteristics of people who stopped treatment

Case	Sex	Age	treatment initiation time	Stop Date	Main reason of stopping ARVs
C1	Female	36	2007	2019	Was not receiving good services from the nurse taking care of PLHIV at health facility
C2	Female	34	2015	2019	She was away from her home and was scared of the stigma then she stopped her ARVs. Since she get lost to follow-up for a while, she was afraid to be blamed by HCP once she returns at HF…
C3	Female	37	Do not remember	Not remember	Negligence: she changed residence and went without transfer and was

					back to initial health facility and at the end stopped her treatment
C4	Female	49	08th April 2020	April 2020	The mother of 4 children stopped ARVs due its side effects (dizziness) and not able to work while she was the only one to feed the family.
C5	Male	52	08 April 2019	08 Sept 2019	Community stigma and discrimination: He has been stigmatized by the community, refused him casual work. “I worked in quarries for 15 years, when they knew that I was HIV, they stopped me”
C6	Female	48	2012	2017	Internal stigma: Discordant couple woman was scared that husband can know. Taking drug can disclose her HIV status and fearful and shamed of becoming the source of HIV infection within household
C7	Male	30	2018	2020	Internal stigma. The patient used to take ARVs very far from home (2-3 hrs walk)
C8	Female	46	2018	Do not remember – but did not finish her one month treatment	Side effects: Dizziness after starting ARVs was reason of stopping them

“I am tired of keeping this secret and I’m scared of telling my husband that I’m HIV positive because I don’t know his HIV status and he told me that he is HIV negative. I wish he became positive as me for it is in that situation I can at least blame him of bringing HIV. I

know he has multiple sexual partners and when he becomes HIV positive he will not complain much- Case 6 said.

SECTION III. LIMITATIONS

Like any other survey or research, the stigma index 2.0 had some limitations:

(i)The survey did not include PLHIV with mental problem who might face double stigma

(ii) the sample frame could not be able to include transgender and drug users PLHIV

(iii)he Sample frame for people who know their HIV status at least for 12 months is challenging, to do it, requires recency testing. This is why the survey used a proxy of PLHIV enrolled into care for at least 12 months.

(iv) there was no way to confirm that participants from PLHIV not enrolled at HF are really HIV positive;

(v) The existing SDI tool developed by GNP+ and its partners does not generate an index.

(vi) PLHIV who not enrolled into care were not included in the quantitative part of the survey

CHAPTER IV. CONCLUSION AND RECOMMENDATIONS

4.1. Conclusion

HIV related stigma and discrimination have been recognized as the main barriers for HIV prevention, care and treatment. This survey provides insight into the level of stigma and discrimination experienced by PLHIV in Rwanda. The findings demonstrate:

- Encouragingly, HIV related stigma and discrimination has generally reduced in Rwanda as the composite indicator rates very low (13.2). Most of PLHIV interviewed noted a positive change in terms of decrease HIV related stigma and discrimination compared to 10years back.

- The persons who knew HIV status of PLHIV without their consent doubled between 2009 and 2020 which might result from the scale-up of HIV services countrywide to the decentralized level of the health system for the last decade. Positive discrimination for PLHIV, for instance financial support of PLHIV and their children, openness of PLHIV in associations/networks on their HIV status may also allow people to know their HIV status and thus contribute disclosure of their HIV status without consent.

- HIV related stigma and discrimination continues to be a problem to some categories of PLHIV including young people, women and key populations (FSW and MSM).

- Considering the sample of the survey there was a low socio-economic status, low level of education and low rate of employement among people living with HIV. Key populations are facing double stigma.

- Half of PLHIV interviewed reported being unable to meet their basic needs some of the times.

- Internal stigma is still persistent among PLHIV as they fear to disclose their HIv status. stigma. PLHIV knowledge of the laws and policies that protect PLHIV needs to be increased.

- PLHIV still need to be aware of policies and laws that protect the rights so that they can be aware of their rights and responsibilities and be able to take action as necessary.

4.2. Recommendations

From the conlusions, the following recommendations are formulated:

To RRP+, HIV national program and its partners:

- Prioritize Specific and appropriate interventions for young people, women and Key populations(MSM and FSW) in strategic planning, funding and programs implementation aiming at reducing stigma reduction
- Reinforce counselling, Psychological support to reduce the internalized stigma
- Provide Education and raise awareness of PLHIV on the laws and policies that protect them
- Develop innovative and strengthen existing economic sustainable programs to allow PLHIV meet their basic needs.
- Include HIV related stigma and discrmination indicators in the existing HIV M&E system to monitor and evaluate progress.
- Conduct futher investigations of underlying factors of disclosure of HIV status with consent

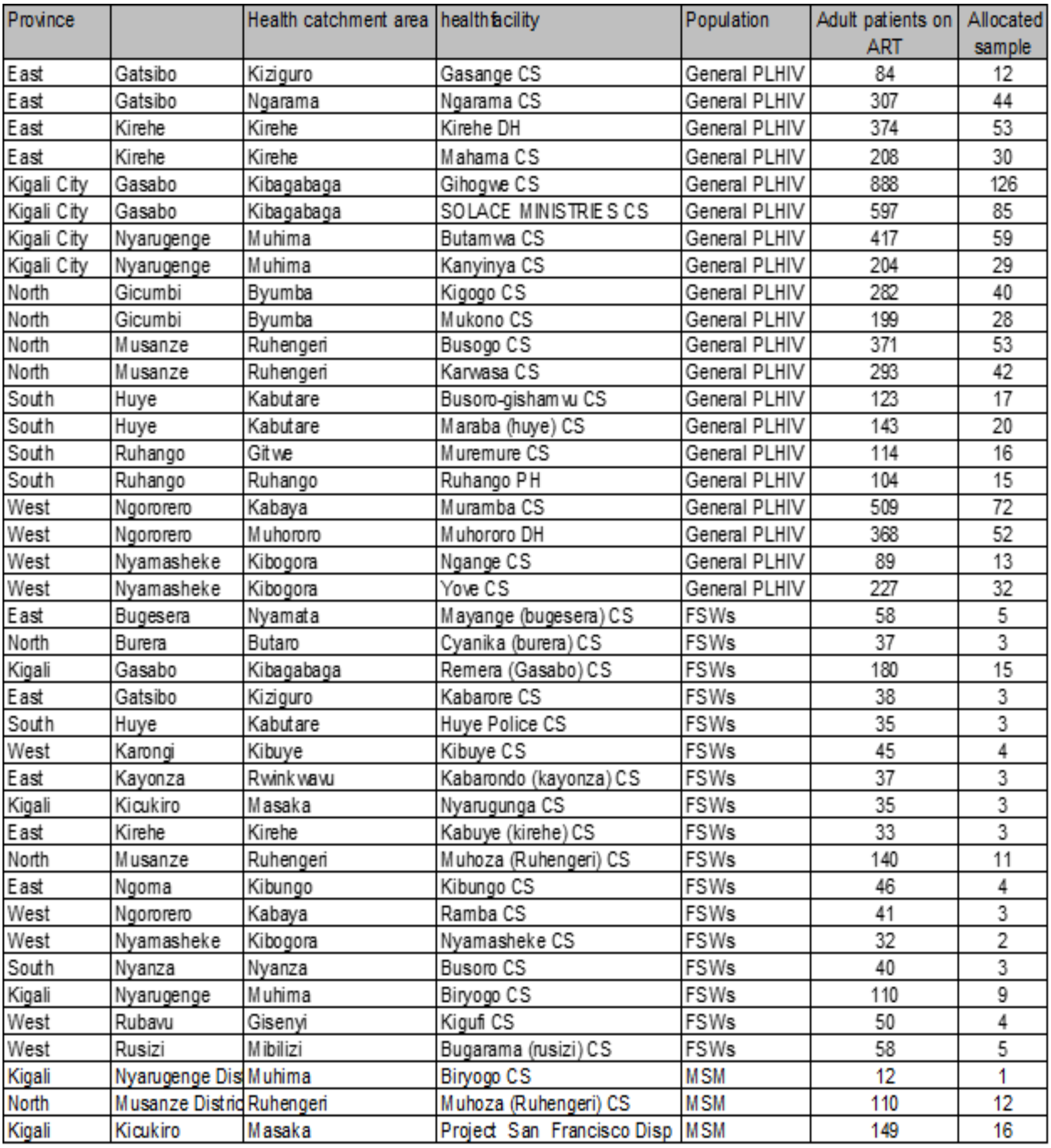
To GNP+

- Review the SDI tool so that it generates Index(Compiste indicator).This would be used to compare the levels of stigma with other countries

APPENDICES

APPENDIXES

Appendix 1. List of selected Health Facilities and allocated sample size



Province		Health catchment area	healthfacility	Population	Adult patients on ART	Allocated sample
East	Gatsibo	Kiziguro	Gasange CS	General PLHIV	84	12
East	Gatsibo	Ngarama	Ngarama CS	General PLHIV	307	44
East	Kirehe	Kirehe	Kirehe DH	General PLHIV	374	53
East	Kirehe	Kirehe	Mahama CS	General PLHIV	208	30
Kigali City	Gasabo	Kibagabaga	Gihogwe CS	General PLHIV	888	126
Kigali City	Gasabo	Kibagabaga	SOLACE MINISTRIES CS	General PLHIV	597	85
Kigali City	Nyarugenge	Muhima	Butamwa CS	General PLHIV	417	59
Kigali City	Nyarugenge	Muhima	Kanyinya CS	General PLHIV	204	29
North	Gicumbi	Byumba	Kigogo CS	General PLHIV	282	40
North	Gicumbi	Byumba	Mukono CS	General PLHIV	199	28
North	Musanze	Ruhengeri	Busogo CS	General PLHIV	371	53
North	Musanze	Ruhengeri	Karwasa CS	General PLHIV	293	42
South	Huye	Kabutare	Busoro-gishamvu CS	General PLHIV	123	17
South	Huye	Kabutare	Maraba (huye) CS	General PLHIV	143	20
South	Ruhango	Gitwe	Muremure CS	General PLHIV	114	16
South	Ruhango	Ruhango	Ruhango PH	General PLHIV	104	15
West	Ngororero	Kabaya	Muramba CS	General PLHIV	509	72
West	Ngororero	Muhororo	Muhororo DH	General PLHIV	368	52
West	Nyamasheke	Kibogora	Ngange CS	General PLHIV	89	13
West	Nyamasheke	Kibogora	Yove CS	General PLHIV	227	32
East	Bugesera	Nyamata	Mayange (bugesera) CS	FSWs	58	5
North	Burera	Butaro	Cyanika (burera) CS	FSWs	37	3
Kigali	Gasabo	Kibagabaga	Remera (Gasabo) CS	FSWs	180	15
East	Gatsibo	Kiziguro	Kabarore CS	FSWs	38	3
South	Huye	Kabutare	Huye Police CS	FSWs	35	3
West	Karongi	Kibuye	Kibuye CS	FSWs	45	4
East	Kayonza	Rwinkwavu	Kabarondo (kayonza) CS	FSWs	37	3
Kigali	Kicukiro	Masaka	Nyarugunga CS	FSWs	35	3
East	Kirehe	Kirehe	Kabuye (kirehe) CS	FSWs	33	3
North	Musanze	Ruhengeri	Muhoza (Ruhengeri) CS	FSWs	140	11
East	Ngoma	Kibungo	Kibungo CS	FSWs	46	4
West	Ngororero	Kabaya	Ramba CS	FSWs	41	3
West	Nyamasheke	Kibogora	Nyamasheke CS	FSWs	32	2
South	Nyanza	Nyanza	Busoro CS	FSWs	40	3
Kigali	Nyarugenge	Muhima	Biryogo CS	FSWs	110	9
West	Rubavu	Gisenyi	Kigufi CS	FSWs	50	4
West	Rusizi	Mibilizi	Bugarama (rusizi) CS	FSWs	58	5
Kigali	Nyarugenge Dis	Muhima	Biryogo CS	MSM	12	1
North	Musanze Distric	Ruhengeri	Muhoza (Ruhengeri) CS	MSM	110	12
Kigali	Kicukiro	Masaka	Project San Francisco Disp	MSM	149	16

Appendix 2. Interview guide

Interview guide for FGDs

Introduction

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

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

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

Now, to make it easy to refer to each other during the discussion, please think of a name(not your real name) by which you would like to be called during this discussion – I will call myself _________, and I will stick that name on me (as you do it). Please do the same.

Questions

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

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

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

4. Which group of people are mostly affected by HIV related stigma in your area? Probe; (Women, Children, Youth, Sex Workers, MSM, people living with Disabilities)

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

   Probe;

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

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

Probe;

a. Do you know cases of HIV related?

b. In terms of access to work as well as health facilities, are people living with HIV/AIDS receiving the same treatment as well as being given opportunities similar to people who are negative in this community?

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

Probes;

a. If Yes/No. Why do you think are they comfortable or uncomfortable?

b. What are the personal experiences you have personally had or witnessed within the society?

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

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

9. We are now nearing to the end of our discussion (Recommendations). The views you have shared will be extremely useful to us. In your view what do you recommend that should be done to curb stigma and discrimination among the PLHIV 11. Closure): Is there anything else you would like us to know, which we did not talk about with regards to stigma and discrimination among think will PLHIV

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

Appendix 3. Ibibazo byakoreshejwe mu biganiro byo mu matsinda

Intangiriro

Mwaramutse/Mwiriwe. Mwakoze kuba mwaje muri iki kiganiro. Nitwa _____ na mugenzi wanjye turi kumwe yitwa_________ Mpagarariye itsinda ry'ubushakashatsi ku ihezwa n'akato bikorerwa abafite virusi itera SIDA.

Kuko tudashaka ko hari uhuza amazina yawe n'ibizubizo watanze,ntamazina y'umutntu tuei bwandike. Mu isesengura, tuzahuza amakuru yose mwaduhaye kandi tuyabike mu buryo bw'ibanga.

Dukeneye ibitekerezo bya buri wese uri aha – bityo mwisanzure, kandi ni byiza ko buri wese yubaha igitekerezo cya mugenzi we, nubwo ibitekerezo bye byaba binyuranye n'ibyawe –Ni ibisanzwe kugira ibitekerezo binyuranye ko byo tugiye kuganiraho.

Kugirango tuganire neza kandi buri wese ashobora guhamagara undi, tekereza izina wiyita(ritari izina ryawe bwite) bari buguhamagare mu gihe cy'ikiganiro – Njyewe ndiyita __________, kandi ndakomeza iryo zina mu gihe cy'ikiganiro. Namwe mubikore nkuko.

Ibibazo

1. Hari ibintu byinshi abantu bavuga ku bafite virusi itera SIDA. Ni biki waba warumvise babavugaho?

2. Ese wowe ihezwa n'akato bishingiye kuri virusi itera SIDA ari iki?

3. Ku bwawe, abafite virusi itera SIDA baba bakorerwa ihezwa n'akato bishingiye ku kuba bafite virusi itera SIDA? Yego/oya, Niba ari yego cg oya Kubera iki?

4. Ni ikihe cyiciro cy'abantu bafite virusi itera SIDA ubona bibasiwe n 'ihezwa cg akato?(Abana,abagore, urubyiruko,Indaya,Abafite ubumuga,abatinganyi…), Kubera iki?Ubona biterwa n'iki?

5. Reka tuvuge ubwoko bw'ihezwa n'akato bikorerwa abafite virusi itera SIDA. Ubwoko bw'ihezwa n'akato bikunze kukugaragarira n'ibihe? (i)Guhezwa mu birori bitandukanye: (ii)Ubukwe,gushyingura, (iii)mu matsinda y'abantu, (iiii)Guhezwa muri gahuda zo gusenga,(iv)Guhezwa muri gahuda z'umuryango; (v)Kwirukanwa mu kazi cyangwa ku ishuri(vii) Guhihoterwa ku mubiri, gutukwa cyangwa gutezwa ihungabana…….

6. Tuvuge kuli servisi zihabwa abahawe ihezwa n'akato. Iyo hari abakorewe ihezwa n'akato gashingiye ko bafite virusi itera SIDA bafashwa iki, gute?

   Hari uwo cg abo byabayeho waba uzi?

   Ku bijyanye no guhabwa akazi akazi, kwiga cg changwa guhabwa servisi ku avuriro abafite virusi itera sida bafatwa kimwe n'abandi bantu? Ese bahabwa amahirwe kimwe n'abandi muri sosiyete?

7. Uratekereza ko aho mutuye cga mukorera cg mwiga abafite virusi itera SIDA biboroheye cyangwa batekanye kubwira aabantu ko bafite virusi itera SIDA

   Niba ari Yego cg Oya, kuki utekereza ko biboroheye cyangwa bitaboroheye?

   Ni ibihe bintu wowe ubwawe byakubayeho cyangwa wiboneye n'amaso bijyanye n'ihezwa n'akato ku bafite virusi itera SIDA

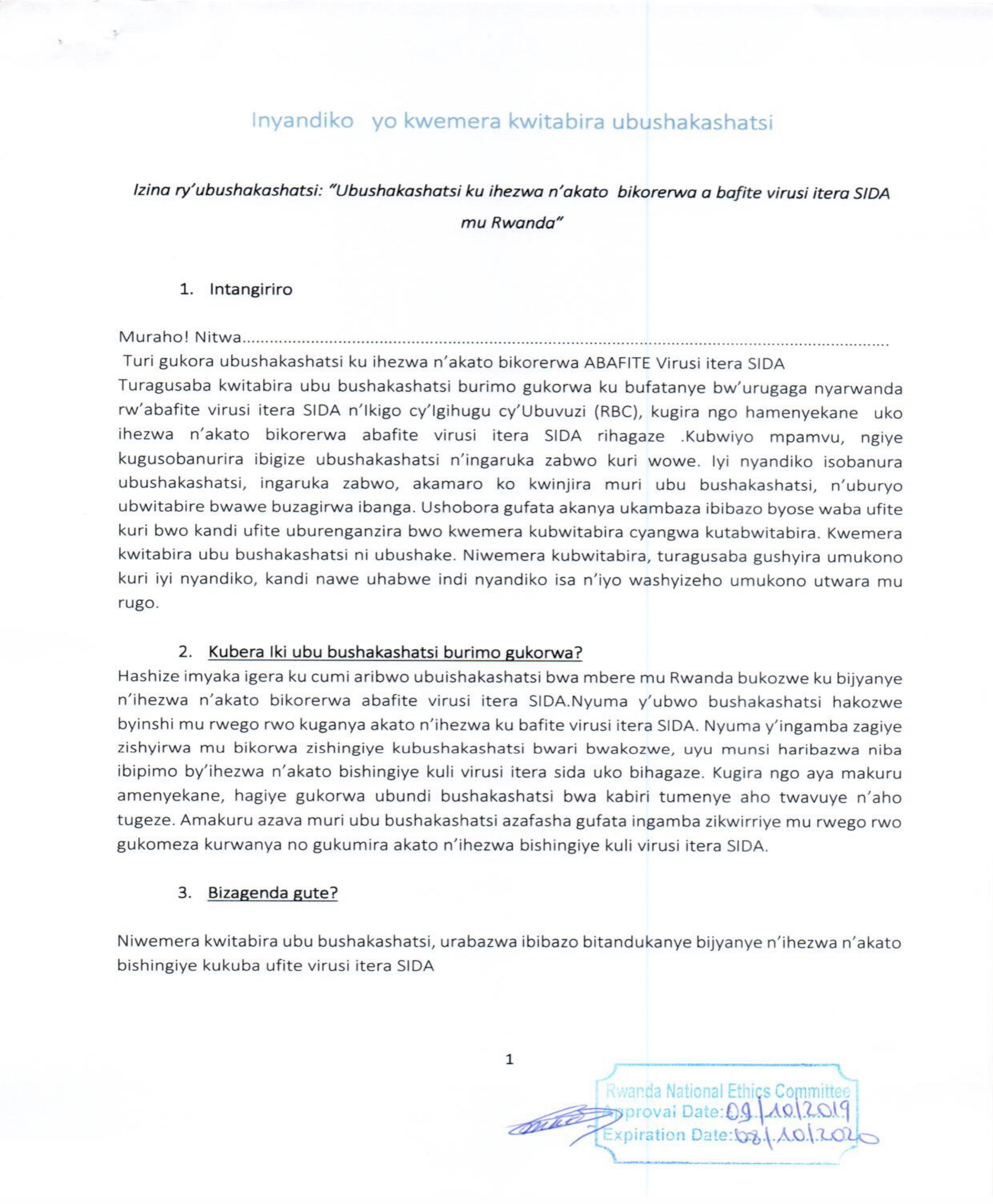
8. Waba uzi niba hari amategeko arwanya ihezwa n'akato bikorerwa abafite virusi itera SIDA?

   Ese urumva hari impinduka zakorwa mu mategeko kubwiyo pmavu, niba aribyo niyihe mpinduka wowe wifuza?

9. Turi kugana ku musozo w’ibgiganiro twagiranye. Ibyo mwatubwiye byiose n’ingirakamaro. Ku bwawe ni iki watanga nk’icyifuzo cg ibyifuzo mbere yuko dusoza. Ese hari ikindi wifuza kumenya tutaganiriyeho mbere ku bijyanye n’ihezwa n’akato bikorerwa abafite virusi itera SIDA

Turabashimiye cyane kuba mwitabiriye ibi biganiro n’ibitekerezo mwatanze!

Appendix 4. Informed consent form



Inyandiko yo kwemera kwitabira ubushakashatsi

Izina ry'ubushakashatsi: "Ubushakashatsi ku ihezwa n'akato bikorerwa a bafite virusi itera SIDA mu Rwanda"

1. Intangiriro

Muraho! Nitwa..
Turi gukora ubushakashatsi ku ihezwa n'akato bikorerwa ABAFITE Virusi itera SIDA
Turagusaba kwitabira ubu bushakashatsi burimo gukorwa ku bufatanye bw'urugaga nyarwanda rw'abafite virusi itera SIDA n'Ikigo cy'Igihugu cy'Ubuvuzi (RBC), kugira ngo hamenyekane uko ihezwa n'akato bikorerwa abafite virusi itera SIDA rihagaze .Kubwiyo mpamvu, ngiye kugusobanurira ibigize ubushakashatsi n'ingaruka zabwo kuri wowe. Iyi nyandiko isobanura ubushakashatsi, ingaruka zabwo, akamaro ko kwinjira muri ubu bushakashatsi, n'uburyo ubwitabire bwawe buzagirwa ibanga. Ushobora gufata akanya ukambaza ibibazo byose waba ufite kuri bwo kandi ufite uburenganzira bwo kwemera kubwitabira cyangwa kutabwitabira. Kwemera kwitabira ubu bushakashatsi ni ubushake. Niwemera kubwitabira, turagusaba gushyira umukono kuri iyi nyandiko, kandi nawe uhabwe indi nyandiko isa n'iyo washyizeho umukono utwara mu rugo.

2. Kubera Iki ubu bushakashatsi burimo gukorwa?

Hashize imyaka igera ku cumi aribwo ubuishakashatsi bwa mbere mu Rwanda bukozwe ku bijyanye n'ihezwa n'akato bikorerwa abafite virusi itera SIDA.Nyuma y'ubwo bushakashatsi hakozwe byinshi mu rwego rwo kuganya akato n'ihezwa ku bafite virusi itera SIDA. Nyuma y'ingamba zagiye zishyirwa mu bikorwa zishingiye kubushakashatsi bwari bwakozwe, uyu munsi haribazwa niba ibipimo by'ihezwa n'akato bishingiye kuli virusi itera sida uko bihagaze. Kugira ngo aya makuru amenyekane, hagiye gukorwa ubundi bushakashatsi bwa kabiri tumenye aho twavuye n'aho tugeze. Amakuru azava muri ubu bushakashatsi azafasha gufata ingamba zikwirriye mu rwego rwo gukomeza kurwanya no gukumira akato n'ihezwa bishingiye kuli virusi itera SIDA.

3. Bizagenda gute?

Niwemera kwitabira ubu bushakashatsi, urabazwa ibibazo bitandukanye bijyanye n'ihezwa n'akato bishingiye kukuba ufite virusi itera SIDA

1

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4. Ni akahe kamaro kwitabira ubu bushakashatsi?

Amakuru utanga niyegeranywa hamwe n'ayabandi, hari ingamba zizafatwa mu gukomeza kurwanya ihezwa n'akato. Ibyo bizagira ingaruka nziza mu mibereho y'abafite virusi itera SIDA , n'abagezweho n'ingaruka zayo

5. Mbese ni ngombwa ko nitabira ubu bushakashatsi?

Kwitabira ubu bushakashatsi ni ngombwa ariko nadi ni ubushake. Ushobora guhitamo kutabwitabira. Kuba wahitamo kutabwitabira nta ngaruka bizagira kuri serivisi z'ubuzima usanzwe uhabwa. Niwemera kubwitabira, wemerewe no kuba wabuvamo igihe cyose ushakiye ntankurikizi kubijyanye na serivisi wahabwaga muri iri vuriro.

6. Ni gute nzagiririrwa ibanga ?

Amazina yawe, nimero yawe ya telefone n'umwirondoro w'aho utuye ntabwo bizafatwa ngo bishyirwe muri ubu bushakashatsi. Ubushakashatsi buzashyira ahagaragara raporo y'abantu bose muri rusange.Urahabwa umubare wihariye ujyanye n'ubu bushakashatsi, ari na wo uri bukoreshwe mu mwanya w'izina ryawe. Amakuru yose turi bufate azagirwa ibanga kandi abikwe mu buryo bw'ibanga. Uri buhabwe inyandiko isa n'inyandiko washyizeho umukono kugira ngo uzayikoreshe mu gihe waba uyikeneye. Wemerewe kubaza ibibazo waba ufite ku bijyanye n'ubu bushakashatsi mbere yuko dukomeza.

7. Abo wahamagara?

Ushobora kubaza ibibazo ku byerekeye ubu bushakashatsi uyu munsi cyangwa n'ikindi gihe ubyifuje. Niba ufite ibibazo byerekeye ubu bushakashatsi, cyangwa hari ingaruka ubona bwakugizeho bitewe n'uko wemeye kwitabira ubu ubushakashatsi, ushobora guhamagara:

- Dr HABIMANA Dominique Savio, Umuyobozi Ushinzwe Gukurikirana no Kuvura Virusi Itera SIDA mu Kigo cy'Igihugu Gishinzwe Ubuzima (RBC) kuri Telefone nimero: 0788732818
- SEMAFARA Sage, Umunyamabanga Nshingwabikoywa wa RRP+ kuri Telefone nimero: 078830 5950

Uramutse kandi ugize ikibazo ku burenganzira bwawe nk'uwemeye kwitabira ubushakashatsi, wahamagara abayobozi muri Komite y'Igihugu irengera uburenganzira bw'abakorerwaho ubushashakatsi, kuri Telefone igendanwa

- Dr. Jean Baptiste Mazarati: 0788309807
- Dr David Tumusiime : 078 874 93 98.

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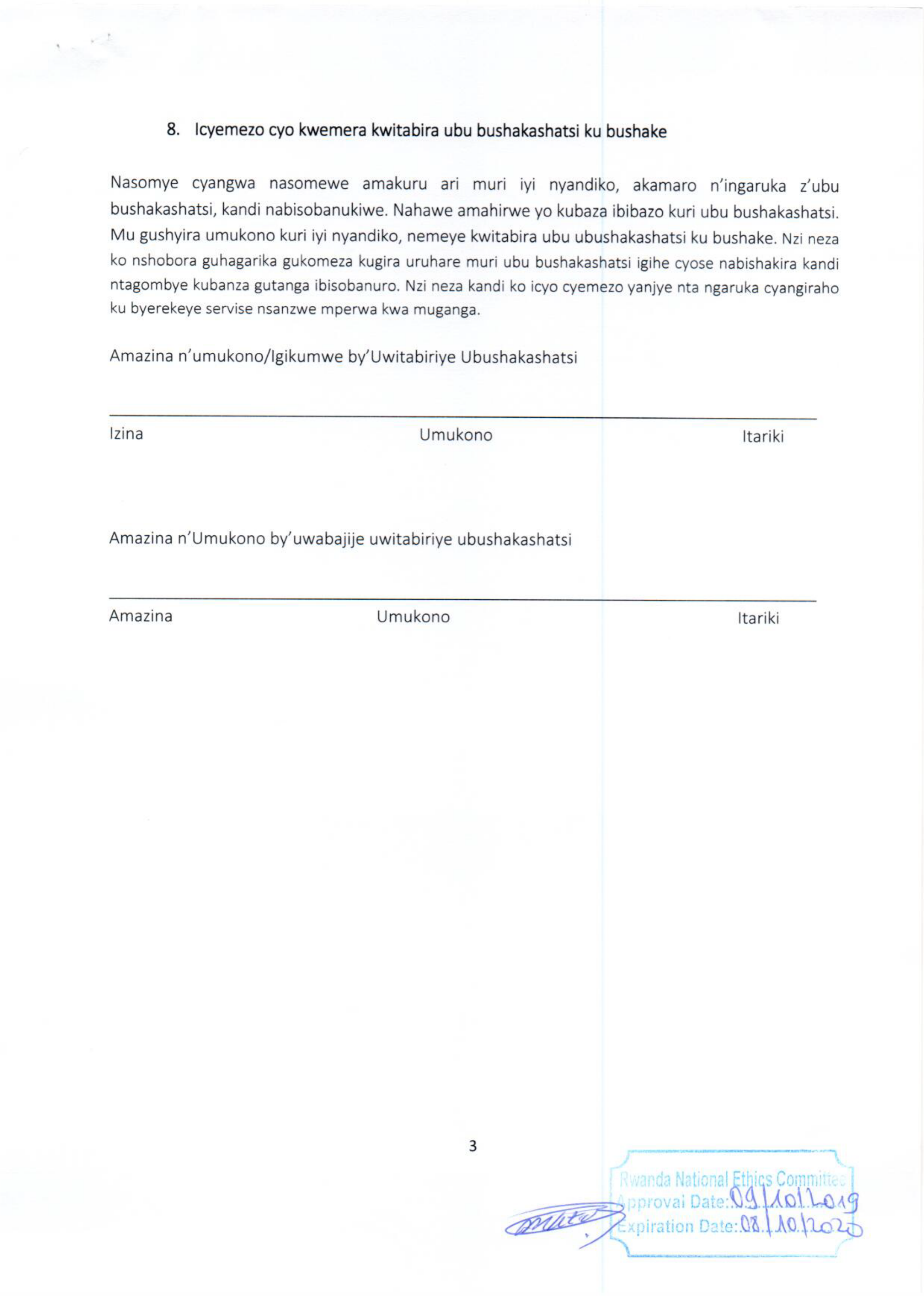

8. Icyemezo cyo kwemera kwitabira ubu bushakashatsi ku bushake

Nasomye cyangwa nasomewe amakuru ari muri iyi nyandiko, akamaro n'ingaruka z'ubu bushakashatsi, kandi nabisobanukiwe. Nahawe amahirwe yo kubaza ibibazo kuri ubu bushakashatsi. Mu gushyira umukono kuri iyi nyandiko, nemeye kwitabira ubu ubushakashatsi ku bushake. Nzi neza ko nshobora guhagarika gukomeza kugira uruhare muri ubu bushakashatsi igihe cyose nabishakira kandi ntagombye kubanza gutanga ibisobanuro. Nzi neza kandi ko icyo cyemezo yanjye nta ngaruka cyangiraho ku byerekeye servise nsanzwe mperwa kwa muganga.

Amazina n'umukono/Igikumwe by'Uwitabiriye Ubushakashatsi

Izina	Umukono	Itariki

Amazina n'Umukono by'uwabajije uwitabiriye ubushakashatsi

Amazina	Umukono	Itariki

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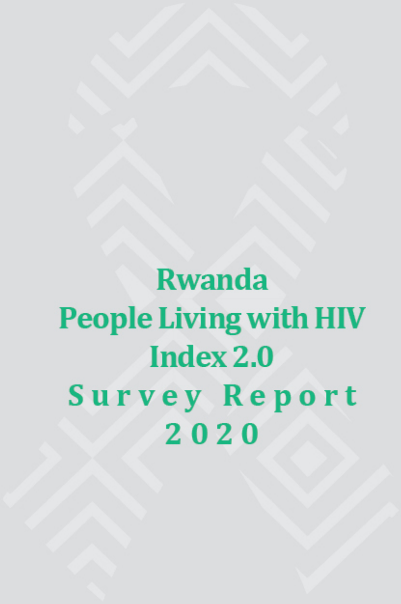

Rwanda
People Living with HIV
Index 2.0
Survey Report
2020