



PEOPLE LIVING WITH HIV STIGMA INDEX:  
RWANDAN STIGMA AND DISCRIMINATION SURVEY REPORT

**July 2009**

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## Lists of acronyms

AIDS	Acquired Immuno Deficiency Syndrome
ART	Anti-Retroviral Treatment
ARV	Anti-Retroviral
AVVAIS	L'Association des Veuves Vulnérables Affectées et Infectées par le VIH/SIDA
CNLS	Commission Nationale de Lutte contre le SIDA
FBO	Faith-Based Organisations
GIPA	Greater Involvement of People Living with HIV/AIDS
HIV	Human Immunodeficiency Virus
ICW	International Community of Women Living with HIV/AIDS
IPPF:	International Planned Parenthood Federation (IPPF)
NGO:	Non-Governmental Organisations
PLHIV:	People living with HIV
PMTCT:	Preventing Mother-To-Child-Transmission of HIV
RDHS :	Rwandan Demographic Health Survey
RRP+ :	Le Réseau Rwandais des Personnes Vivant avec le VIH
SPSS:	Statistical Package for the Social Sciences
UNAIDS:	The United Nations Joint Programme on HIV/AIDS
UNGASS	United Nations General Assembly Special Session on AIDS

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## Acknowledgements

This report is a summary of the findings of a survey on stigma and discrimination for Rwanda conducted in October 2008. The study used the “People Living with HIV Stigma Index” which has been developed by global experts convened by the International Planned Parenthood Federation (IPPF), Global Network of People Living with HIV/AIDS (GNP+), International Community of Women Living with HIV/AIDS (ICW) and the Joint United Nations Programme on HIV/AIDS (UNAIDS), beginning 2005.

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Finally, we would like to thank members of RRP+ who opened their hearts to give us intimate information about themselves during this survey. We thank them for providing the information which will help improve our understanding of stigma and discrimination as part of the AIDS response in Rwanda, the Africa region and elsewhere.

## Executive Summary

This report presents an analysis of information collected on stigma and discrimination against HIV positive members of associations of Le Réseau Rwandais des Personnes Vivant avec le VIH (RRP+) that will contribute to the understanding and reduction of stigma and discrimination in PLHIV. Since stigma and discrimination may act as barriers to access to HIV/AIDS services, the findings of this study will contribute to the improvement of Universal Access to prevention, treatment, care and support in Rwanda, the sub-Saharan Africa region and globally.

HIV-related stigma and discrimination are more increasingly recognised as a huge barrier to combating AIDS in sub-Saharan Africa and elsewhere. Stigma and discrimination are associated with lower uptake of preventive services, testing and counselling; reduced and delayed disclosure of HIV sero status; and postponing or rejecting care, and seeking healthcare services outside one's community for fear of breach of confidentiality (Ogden and Nyblade, 2005; UNAIDS, 2007).

The overall objective of the assessment was to collect information on stigma and discrimination against HIV positive members from the association RRP+ that will contribute to the understanding and reduction of stigma and discrimination in PLHIV. Stigma and discrimination may act as barriers to access to HIV/AIDS services. The specific objectives of the assessment was to document the various experiences of people living with HIV regarding HIV-related stigma and discrimination in Rwanda, and secondly, to provide an evidence base for advocacy, policy change and programmatic interventions to address stigma and discrimination related to HIV.

This is a quantitative descriptive study which analysed the problem of stigma and discrimination amongst members of associations of the Rwanda Network of PLHIV. A simple random sampling technique was employed for this study.

### **Main findings**

The framework that is used for analysis of the data collected and presentation is based on the key thematic areas of the Stigma Index Guide as highlighted below:

**Demographic characteristics of respondents:** The mean duration respondents have been living with HIV was five and a half years. The majority of respondents (64%) reported to have lived with HIV within the last five years. The mean duration involved in a relationship for men was about 2.6 years more than that for women (13.1 years and 10.5 years respectively).

**Perceived experience HIV related stigma and discrimination:** HIV was the main reason (at least 74%) reported for those who felt they experienced discrimination from other people. Other reasons included being internally displaced, being a sex worker, and being an asylum seeker. The discrimination took the form of exclusion from family activities, being gossiped about and physical harassment.

**Access to social services:** Although 87 percent of the respondents reported that they had never been denied health services. Surprisingly, a large percentage (88 percent) of respondents

reported being denied family planning services because of their HIV positive status in the last 12 months.

**Internal stigma and fears:** Forty five percent of respondents reported that they felt ashamed because of their HIV status. The main forms of internal stigma were feelings of guilt, self-blame and low self-esteem. Anticipation of fear of being gossiped, verbally insulted, harassed and/or threatened were higher for females, while more men feared that someone would not want to be sexually intimate with them because of their HIV status.

**Rights, laws and policies:** About a third of respondents interviewed reported that they have had their rights abused because of their HIV-positive status. A third of them said they got a government employee to take action against the abuse in the last 12 months. About 40 per cent of them reported that the matter had been dealt with.

**Effecting change:** There was low knowledge of organisations that help care for people living with HIV. The most widely known organisations were networks of people living with HIV.

**Testing and diagnosis:** A low four percent of the respondents tested to prepare for marriage/sexual relationship. A large percentage tested for other reasons (34%), followed by those who tested due to illness or death of husband/wife from HIV (14%). However, the majority (79%) reported deciding on their own to test for HIV.

**Disclosure and confidentiality:** Nearly 60 per cent of respondents reported that they often “felt” pressure to disclose their HIV status from other individuals not living with HIV (e.g. family members, social workers, and NGO employees).

**Treatment:** Though 46 percent of the respondents described their health as fair, almost one in every four respondents reported having poor health status, seventy-three percent of respondents reported they have access to ARV treatment and 69% reported receiving treatment for opportunistic infections.

**Experience of having children:** Respondents were asked about their reproductive experience, 88 percent reported that they have children. Sadly, almost three quarters of them had children who are HIV-positive.

### **Recommendations:**

The findings from the study recommendations are addressed to the different stakeholders -

#### Ministry of Health/CNLS/RRP+:

1. Most individuals only test when the woman is already pregnant, a sign that unprotected sex has taken place. The data for both males and females suggest that the woman's pregnancy triggered both partners to test. This needs further investigation to understand partner-communication and male involvement in prevention of mother-to-child transmission (PMTCT) programmes. Testing before entering into sexual relationships should also be encouraged.

2. There is a need to develop evidence-informed counselling protocols to help couples with at least one HIV-infected partner to make family planning decisions.
3. There is an opportunity to develop the capacity of networks of PLHIV to influence decision in policies and programmes. The survey results show only 28 per cent of respondents knew of a Rwandan law which protects the rights of PLHIV.
4. The survey results show that some respondents were not aware of PMTCT. There is a need to create more awareness on PMTCT.
5. Over two-thirds of study participants self-reported their health status as either 'fair' or 'poor'. This is typical of developing countries. Self-reported health status is known to be a reasonable indicator of burden of disease and demand for health care services. About half of respondents lived on less than \$1 a day and reported spending at least a day without food. The Government of Rwanda needs to prepare enforcement mechanisms of maintaining quality of life for the general population while specifically ensuring that HIV positive persons are not worse off.

#### Researchers (including IPPF developers of Stigma Guide):

1. It is recommended that in future surveys with PLHIV the following data regarding reproductive behaviour be collected:
  - a. Marriage order (i.e. 1<sup>st</sup>, or 2<sup>nd</sup> marriage) of respondents.
  - b. For those who were previously married, reasons for resolution marriage and/or cause of widowhood.
  - c. Fertility desire of respondents before and after starting to live with HIV.

This information will help better understand family planning decisions and rights of PLHIV, and sexual relationships in the context of HIV risk for couples.

2. There is a need to research more on qualitative aspects of reproductive choices such as family planning, pregnancy termination, and method of giving birth, and feeding practices such as infant feeding practices, from the perspective of mothers and health and social care workers.
3. The study findings show that the majority of respondents reported that the reaction of social workers and health care workers was very supportive. This suggests that stigma and discrimination needs to be understood from the perspectives of different service providers including faith based and community based organisations.

## Background and Introduction

Addressing stigma and discrimination is critical to achieving universal access to HIV prevention, care, support and treatment by 2010, as committed by world leaders in 2001. Stigma is a sign of disgrace or shame and often described as a process of devaluation. A person who is stigmatised is seen as having less value or worth to other people (International Planned Parenthood Federation (IPPF), 2008). UNAIDS (2007) defines HIV-related stigma as a process of devaluation of people living with or associated with HIV and AIDS. Stigma can be projected by other people or can be “felt” or “self-stigmatisation”, and termed ‘internal stigma’.

Discrimination involves treating someone in a different and unjust, unfair or prejudicial way, often on the basis of their actual or perceived belonging to a particular group. It consists of actions or omissions that are a result of stigma and directed towards those individuals who are stigmatised. In other words, discrimination is ‘enacted stigma’ (IPPF, 2008; UNAIDS, 2005). However, a person may feel stigma towards another but s/he decide not to act in a way that is unfair or discriminatory. Discrimination can occur at different levels: individual, family, community or national (UNAIDS 2007).

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

International civil society and organisations such as the International Community of Women Living with HIV/AIDS (ICW), the International Planned Parenthood Federation (IPPF) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) have spearheaded global initiatives to measure stigma and discrimination. They support countries through means such as advocacy, strategic planning, capacity building, and resource mobilisation to address stigma and discrimination faced by people living with HIV (PLHIV). Greater Involvement of People Living with HIV/AIDS (GIPA) is a principle that aims to realise the rights and responsibilities of people living with HIV. The rationale is that involving individuals and communities vulnerable to and infected by HIV will improve the relevance, acceptability and effectiveness of programmes. The principle was first advocated in 1983 by PLHIV in Denver and formalised at the 1994 Paris AIDS summit and endorsed in 2001 by the United Nations General Assembly special session that brought together 189 UN member countries, including Rwanda, as part of the Declaration of Commitment on HIV/AIDS (UNAIDS, 2007). This commitment encompasses global, regional, and country level responses with regard to prevention, care, treatment, and impact mitigation and requires the cooperation of governments, private industry and labour groups, faith-based organisations (FBOs), non-governmental



organisations (NGOs), human rights groups, and other civil society entities, including organisations of people living with HIV.

The AIDS policies and strategic plans for the Government of Rwanda have especially classified PLHIV as a priority group for prevention, treatment, care and support (CNLS, 2005, 2006). There are about 1500 associations of PLHIV in Rwanda (CNLS, 2008). About 1000 of these associations are members of the Rwandan Network of PLHIV (Le Réseau Rwandais des Personnes Vivant avec le VIH, RRP+). The membership of these associations comprises 90% women (UNGASS Report, 2007). One such organisation is "L'Association des Veuves Vulnérables Affectées et Infectées par le VIH/SIDA » AVVAIS, founded in 2002 to foster care for people infected or affected by AIDS epidemic, especially widows. In the UNGASS report for Rwanda for 2006 - 2007 it was noted that membership of PLHIV associations and micro-credit schemes has enabled PLHIV to feel less isolated and has helped reduce the effects of stigma and discrimination (CNLS, 2008). However, there is also anecdotal evidence of signs of stigma and discrimination faced by members of associations of PLHIV. This study will help to clarify and provide some quantitative information on the extent of the problem of stigma and discrimination among PLHIV in Rwanda.

The Rwanda Demographic and Health Survey of 2000 and 2005 collected some information on accepting attitudes towards those living with HIV which are a composite of four questions: willing to care for family member sick with AIDS; if would buy fresh vegetables from a shopkeeper with AIDS; allowing a female teacher who is HIV+ but not sick to continue teaching in school; and being not secretive about family member's HIV status. In 2005 it was noted that 46% of females and 51% of males had accepting attitudes towards those living with HIV (Institut National de la Statistique du Rwanda (INSR) and ORC Macro, 2006). These results are representative of the attitudes of the general population regardless of their HIV sero-status. It is important to learn from the voices of PLHIV in order to develop stigma-reduction programmes that address their specific concerns. This research project supports the principle of GIPA by allowing PLHIV to plan and conduct a study with other PLHIV to document their experiences regarding stigma and discrimination for an effective AIDS response in Rwanda. The results from the study will provide a powerful advocacy tool regarding stigma and discrimination experienced by PLHIV

## Overall objective

To collect information on stigma and discrimination against HIV positive members of associations of RRP+ that will contribute to the understanding and reduction of stigma and discrimination in PLHIV. Since stigma and discrimination may act as barriers to access to HIV/AIDS services. The findings of this study will contribute to the improvement of universal access to prevention, treatment, care and support in Rwanda, sub-Saharan Africa region and globally.

## Specific objectives:

1. To document the various experiences of people living with HIV regarding HIV-related stigma and discrimination in Rwanda.
2. To provide an evidence base for advocacy, policy change and programmatic interventions to address stigma and discrimination related to HIV.

## Methods

This is a quantitative descriptive study intended to analyse the problem of stigma and discrimination amongst members of associations of the Rwanda Network of PLWHA. This study used the Stigma Index Survey Questionnaire to conduct interviews among PLHIV in Rwanda. It is a preliminary study from which expected viable information would improve on operational programmes and services that are rendered by RRP+. Furthermore, the same information could serve as a basis for larger and more in-depth studies at national level. Thus the study does not aim at generalising the findings at the whole population of the PLHIV in Rwanda.

## Study design

### Study population

People living with HIV, who are members of recognised associations of PLHIV in Rwanda and who are 18 years old and above.

## Sampling

### Sampling techniques

A simple random sampling was the sampling technique for this study. EPI-INFO software was used to determine the required sample for this study. The steps below were used to determine the sample size:

- According to RRP+ report (2008), there were 77 861 members and 49 507 (63.7%) of them were HIV positive.
- Fifty two percent was the average of expected proportions of stigma and discrimination problem in men (54%) and women (49%) (DHS, 2005).
- Confidence interval at 95%.
- Precision at 2.5% (this was set to ensure the problem in a maximised/larger study population).

This procedure yielded a sample size of 1 638 PLHIV. The sample size was rounded up in order to account for non-responses which rate was estimated at 10%.

### Sampling of districts

A random selection of two districts (one rural and one urban) per province was carried out. Thus 10 districts (please refer to list of districts in Appendix 2) in total will constitute the sample size and it represents 1/3 of the total districts of the country. Rwanda has five provinces including Kigali City and 30 districts.

## Sampling of associations

Based on the sampling technique described above the criteria for selecting associations, to ensure equal representation, was as follows:

- Association with at least 50 members living with HIV. This figure was based on the average of the number of PLHIV per association of RRP+ (49 597/ 1128);
- The association should have been in existence for at least two years;
- Association must be a member of the network of people living with HIV (RRP+); and
- Association must be composed of males and females.

## Sampling of individuals

In order to determine the number of PLHIV from associations, the following items were considered:

- Average of association per district: 37.6 (total number of associations over total number of districts).
- Estimated associations in 10 districts: 376.
- Average of PLHIV per association: 44 (Total number of PLHIV over Total number of associations).
- Target population which included the estimated number of PLHIV in 10 districts: 16544 (Number of estimated associations per district \* 10 selected districts \* the average of PLHIV per association).
- Proportion of sample size in estimated number of PLHIV in 10 districts: 9% (study sample over the target population).

Therefore 9% was applied at each selected association to determine the number of PLHIV to be drawn from the same association. Thereafter a simple random selection was applied to pick up names of individuals. This sampling was based on a sampling frame [of HIV positive members] of the selected association.

In taking into account the already known under-representation of males within associations of RRP+ (approximately 10%), any male that is HIV positive and member of a selected association of PLHIV was purposely included in the sample.

## Data collection instruments

The study used the “People Living with HIV Stigma Index” which has been developed by global experts convened by IPPF, Global Network of People Living with HIV/AIDS (GNP+), ICW and UNAIDS beginning 2005 (IPPF, 2008). The English and French versions of the index are available from the website: [www.stigmaindex.org](http://www.stigmaindex.org) or [www.ippf.org](http://www.ippf.org). This index allows collecting information from people living with HIV to: document their experiences; compare experiences across countries; measure changes over time; and provide sound evidence for policy and programme interventions addressing HIV-related stigma and discrimination. The index also focuses on the sexual and reproductive health and rights of people living with HIV.

The Index is designed in such a way that case studies can be identified for follow-up using qualitative methods. Thus the index can employ both quantitative and qualitative research methods.

The questionnaire is divided into three sections, upon which the analysis of data for this report is based:

- Section 1: General information about the respondent and her/his household.
- Section 2: Focuses on reported experience over the last year of PLHIV of HIV related stigma and discrimination:
  - internal stigma (felt or internalized stigma which can lead to low self-esteem and depression);
  - the protection of the rights of PLHIV through law, policy and/or practice; and
  - effecting change in their household and community in responding to stigma and discrimination.
- Section 3: indicators focusing on stigma and discrimination over the last year related to HIV testing, disclosure and the provision of health care.

## Administration of data collection instruments

AVVAIS provided secretarial support for the survey. AVVAIS initiated the study and collaborated with RRP+, the umbrella body in the implementation of the survey. The study was funded by UNAIDS with technical assistance from CNLS.

Representatives of the Rwanda Network of PLHIV (RRP+) were responsible for data collection and senior researchers supervised them. They were chosen because of their experience in dealing with community AIDS problems and have a decentralised representation covering the whole country. A large number of them had university degrees and had some data collection experience. The fieldwork was conducted between 12 October, 2008 and 28 October 2008 by a team of 20 fieldworkers (see Appendix 1 for list of research team).

Questionnaires were filled by the interviewer with the interviewee sitting next to each other as equal partners. IPPF recommends that the interviewee fills their own questionnaire with the assistance of the interviewer in what is called '**side-by-side**' interview. It is argued that this helps to establish an equal relationship between the researcher and researched working together as partners and experiencing the research process together. This follows the Greater Involvement of People Living with HIV (GIPA) principle since both partners here are living with HIV. However, about a third of women aged 15 years and older are illiterate in Rwanda (Institut National de la Statistique du Rwanda (INSR) and ORC Macro, 2006). In cases where the respondent is not able to read and write the interviews were conducted by PLHIV data collectors. This allowed consistency and the keeping of the recommended 'side-by-side' seating position of partnerships.

It was originally planned that qualitative interviews would be done simultaneously with the survey. The data collectors were expected to have some skills in qualitative research interviewing skills. However, it was felt that identifying qualitative questions needed more time and analytical skills.

This report identifies a number of research questions which can be studied further using qualitative methods.

The research team comprising RRP+ representatives and peer interviewers underwent a 3-day training (8 to 10 October, 2008) held in Kigali before commencing data collection. One day was dedicated to pre-testing the questionnaire instrument to ensure validity and reliability of the instruments. This exercise took place at Kacyiru Sector near RRP+ headquarters with members of one of the associations of PLHIV. Members were invited in advance to a church for interviews with the data collectors. The research team had a feedback session and clarified areas of challenges such as understanding of some questions.

## Translation

The data collection instrument was translated into the local language (Kinyarwanda) prior to training of research assistants and data collection. Original questionnaires in both English and French languages were used to clarify some Kinyarwanda translations. The data collection team reviewed the whole questionnaire during the training to ensure that the translation is valid. Special attention was made to translate terms of 'stigma and discrimination' into a culturally appropriate way. The pre-test and review of the process conducted as part of the training ensured the validity of the instruments and proper translation.

## Data analysis plan

As soon as the questionnaires were administered, the supervisor did quality checks while in the field and the questionnaire was sent to a central data management centre at AVVAIS offices. The data were entered and processed using SPSS (Statistical Package for the Social Sciences). A dedicated data processing team of six people entered data in a database created for the questionnaire in SPSS. SPSS was used to produce frequencies, proportions and cross-tabulations and basic Chi-Squared test for indicating statistical significance of differences of data categories. The analysis process helped to identify experiences of the whole dataset and make comparisons across groups based on the information collected in the three sections of the index; individual characteristics in relation to experience over the last year of PLHIV of HIV related stigma and discrimination; and use of HIV testing, AIDS treatment and other health services. The report is based on bivariate analysis only showing the relationship of two or more variables without controlling for the net effect of all other relevant variables. However, the bivariate analysis indicates the important relationships that can be pursued further using advanced multivariate analysis and qualitative methods.

## Data analysis experience and study Limitations

There are a number of limitations arising from the design, administration and analysis of the study.

## Study design issues:

- The design of this study leaves out those people living with HIV but do not know their status; even if they know their diagnosis, they may not openly live with HIV. The PLHIV who are not members of support groups/associations of PLHIV and not reached by this study may be experiencing different levels of stigma and discrimination than the study is able to assess. However, those who have disclosed their HIV positive status and interviewed in this study, give us an idea of the extent of stigma and discrimination experienced by PLHIV in Rwanda.
- The information collected from this study on stigma and discrimination is from the perspective of the respondents and it is not validated with the people referred to in this survey such as neighbours, landlords, work colleagues, or school teachers, principals and health workers.

## Questionnaire items:

- *Duration living with HIV:* the starting point for the duration may only be the time that the respondent was first tested HIV positive. This does not measure when the person was first infected by the virus. However, this should inform the time from which an individual knew s/he had contracted HIV. In other words, it is the time from which the individual confirmed his/her HIV-status (through HIV testing) to the day the interview was conducted.
- *Current relationship status:* misses out those who have remarried, especially men. In the context of AIDS, it is important about the history of sexual relationships and get the survival or HIV status (if known) of current and partners within a specified number of years (e.g. five years). Revised versions of the survey may have to include marriage/relationship order.
- *Currently sexually active:* while a simple yes/no is important, more important is information on the HIV status of sexual partner and number of sexual partners in the last 12 months. This is important to study the sexual behaviour and HIV prevention in discordant couples. It would also help estimate the extent of multiple concurrent partnerships, which have been recognised as one of the drivers of the epidemic in high HIV prevalence countries of sub-Saharan Africa.
- *Desired fertility:* research shows that there are differences in the determinants of fertility of individuals living with HIV and those who are not (Allen, Serufilira, et al, 1993; Chen, Philips et al, 2001) The Stigma Index should include questions that help measure unmet need for family planning as part of the questions asked on reproductive rights.

## Data collection issues:

- *Selectivity of respondents:* participants in this study were invited for interviews to a central place, and in most cases on a working day. This sample may be selective of respondents who are not employed, or if they are then only those who were able to take time off work.

- *Mix of self-administered and interviewer-administered questionnaire:* the developers of the Stigma Index make a provision group self-administered questionnaires, where feasible, to save data collection time. The Rwanda Stigma Index Team decided to use the self-administered questionnaire approach just before fieldwork started in order to complete the fieldwork within the planned time. The data collection team was well trained to use interviewer-administered questionnaires. The data analysis reveals that some of the inconsistencies in the data findings overall may be from the self-administered questionnaires where quality control could not entirely be assured.
- *Qualitative research:* the Stigma Index design allows for collection of quantitative and qualitative data simultaneously. The scope of the study for Rwanda is limited to the quantitative study component. However, during the quantitative data analysis we particularly identified research questions that need to be followed up using qualitative techniques.

### Data processing and analysis issues:

- *Descriptive/Open ended questions:* in addition to the closed questions in the survey questionnaire, respondents were asked, where applicable, to specify any other responses they had in addition to the listed options. The analysis showed that most of the responses in the 'other (specify)' category already existed. Part of the reason for this duplication is that some of the questionnaires were self-administered by respondents as mentioned above.
- *Data entry experience and challenges faced:* data entry was very challenging and took longer than planned since most of the recruited people for this task were not familiar with the use of SPSS software package. It took time to train, supervise them and correct data entry errors. However, this process helped build the capacity of the local research team in data processing.

### Ethical consideration

The study team applied for ethical clearance from the National AIDS Control Commission (CNLS) ethics committee and the National Research Committee. This was granted after addressing a number of queries that were raised such as: representativeness of sample of respondents; validation of translation of the survey instrument; and challenges of self-administered questionnaire in an environment of limited literacy. Please see letter of clearance attached in Appendix 3

The information sheet and informed consent forms for People Living with HIV Stigma Index were translated in Kinyarwanda and given to respondents. Researchers and research assistants ensured a strong focus on confidentiality. A private space for each interview was ensured. There was not any form of forcing a PLHIV to take part of the study. Before being interviewed respondents were asked to consent to collection and processing of their personal data after being fully informed of the nature of the study, who was involved, how the data would be stored and what the data would be used for. The interviewer stressed that the respondent is free to refuse to be interviewed or withdraw from the interview at any time, or refuse to answer some questions. No names of respondents were recorded. A code only was used to identify individual's

file/questionnaire. Except the research team, no one else was allowed to access respondents' information. The completed questionnaires did not contain any information that would locate the interviewee. As per the Ministry of Health directives, the under 18 years old were not be involved in the study.

## Data validation

After a draft report of the study was prepared a validation workshop was held on 25 May 2009 to discuss the findings. Participants from key stakeholders on AIDS in Rwanda attended the workshop. The report was also circulated to partners to make their comments. Specifically, members of RRP+ from each of the districts where the survey was conducted participated at the workshop. Members of the research team also discussed their experiences of collecting data from the field. Some of the experiences include:

1. Discrimination and stigma experienced by children living with HIV or whose parents are living with HIV or died from AIDS. This was common observation in Northern Province. This is some of experience which was not captured by this Index since the target population was consenting adult respondents.
2. Fatalistic attitude of some people living with HIV. Coupled with poverty, some PLHIV felt that they would die soon.
3. Areas where associations of PLHIV were active, there was more awareness of the needs of PLHIV and support for them.



## SECTION 1: Background characteristics and household composition of People Living with HIV

This section presents general background information about people living with HIV (PLHIV). Table 1 shows the percentage distribution of respondents by age, sex and place of residence. The distribution of age group by sex follows the normal distribution with a peak similar to that of women's fertility at 25-29 years. The differences of the age distribution of men and women suggest that the older men engage in sexual relationships with younger women. The survey involved 1 530 respondents<sup>1</sup>, of which more than half of the respondents (54 percent) live in rural areas, 28 percent live in a village or small town, and 18 percent live in a city or large towns (see Figure 1).

**Table 1: Age and Sex distribution, by place of residence**

Percentage distribution of Age and Sex characteristics by place of residence, Rwanda 2008

Age	Place of residence									
	Rural area		Village		City		Total			
	Male	Female*	Male	Female*	Male	Female*	Male		Female	
							Number	Total	Number	Total
15-19	0.4	2.5	0.9	0.6	0.0	0.0	2	0.5	17	1.5
20-24	0.4	3.4	0.0	5.0	2.8	3.8	3	0.7	44	3.9
25-29	6.0	8.3	4.7	13.8	7.0	11.8	24	5.9	118	10.5
30-39	27.6	41.6	31.8	40.9	16.9	41.7	110	26.8	464	41.4
40-49	42.2	32.4	44.9	29.7	39.4	28.4	174	42.4	346	30.9
50+	23.3	11.7	17.8	10.0	33.8	14.2	97	23.7	131	11.7
Total	100.0	100.0	100	100.0	100.0	100.0		100.0		100.0
Number	232	589	107	320	71	211	410		1120	1530

\* P value < 0.05 statistically significant.

<sup>1</sup> The majority (1120/1530) of the respondents were females. This is expected since majority of registered members of RRP+ in Rwanda are women. The total sample size used may vary in the report because of missing cases/no response for different questions.

**Figure 1: Distribution of respondents according to place of residence, Rwanda 2008**

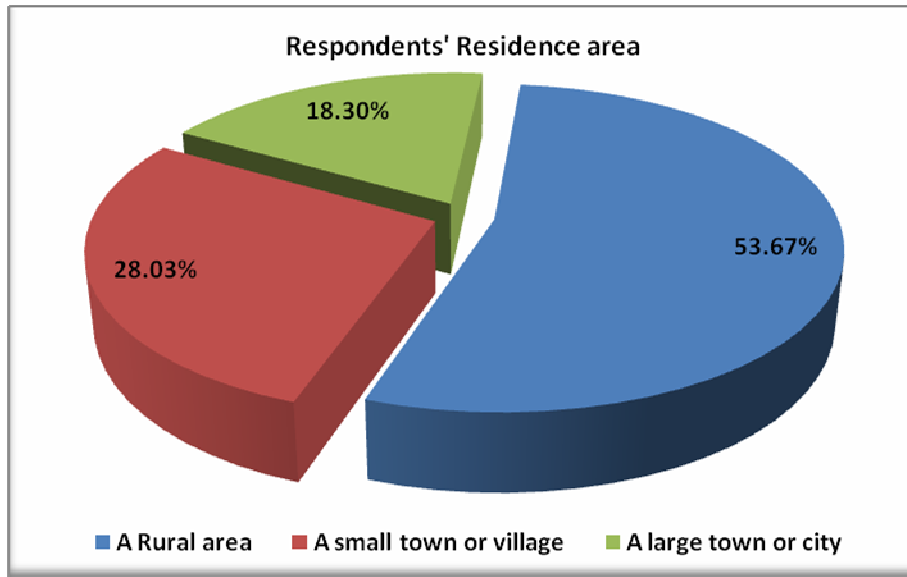


Table 2 shows the percentage distribution of PLHIV by number of people in respondent's household, number of children and youth who are AIDS orphans in respondent's household, average income per month, and number of days without food in respondents household. Only income shows a statistically significant difference between the different categories.

The number of people in respondents household was recorded in terms of presence of individuals of a certain age group. Over 60 percent of the respondents had members aged less than 20 years old in the household. About 694 respondents reported at least having one AIDS orphan in the household.

Poverty is negatively related to health status of individuals. There are a number of measures of poverty. The World Bank and other development organisations use \$1 per day as a measure for the poverty line. About 47 percent of the respondents live on less than a Dollar per day<sup>2</sup>, with more women below the poverty line than men. Another indicator of poverty is the number of days without food. More than half of the respondent reported been without enough food for a day.

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1. <sup>2</sup> Respondents were asked about the average income per month over the last 12 months in Rwandan francs. The amount was converted to dollar (at RWF 500 per Dollar) divided by 30, to give the earning per day. This derives the standard measure of poverty based on the proportion of the population earning less than 1 USD per day.

**Table 2: Characteristics of respondent's household**

Percentage distribution of household composition of people living with HIV by sex. Rwanda, 2008.

CHARACTERISTICS	Frequency		Percentage	
<b>Respondents household which has member in specific age group (N=1511)</b>				
0-14 years	496		32.8	
15-19 years	455		30.1	
20-24 years	361		23.9	
25-29 years	133		8.8	
30-39 years	41		2.8	
40-49 years	12		0.8	
50 years and above	12		0.8	
<b>Total</b>	<b>1511</b>		<b>100.0</b>	
<b>Number of children and youths who are AIDS orphans (N=694)</b>				
1	228		32.9	
2	188		27.1	
3-4	186		26.8	
5+	92		13.2	
<b>Total</b>	<b>694</b>		<b>100.0</b>	
<b>Average income per day*</b>	<b>Male</b>	<b>Female</b>	<b>Total</b>	
Mean	\$5.71	\$3.61	\$4.23	
Std Deviation	12.1	10.2	10.8	
Number	370	948	1318	
Per cent below \$1/day poverty line (n)	38.6%(143)	50.2% (476)	47.0% (619)	
<b>Number of days without enough food (N=1272)</b>				
A day	61.9	58.1	751	59.0
Two days	23.8	28.9	351	27.6
Three days	14.3	12.9	169	13.3
More than four days	0.0	0.1	1	0.1

## Demographic characteristics of people living with HIV

Table 3 shows the percentage distribution of respondent's demographic characteristics and relationship status by sex. There were statistically significant differences for sub groups: current relationship status, current sexual activity, sex practice category, highest educational attainment, and duration involved with partner.

Being married or cohabiting and being widowed were the main relationship status group reported by respondents. It is interesting to note that there were four times more widows than widowers. However, male respondents are three times more likely than female respondents to be married or

cohabiting with a spouse in the same household. This is illustrated in Figure 2. This high percentage of married males may mask remarriage after the death of a spouse.

Furthermore, results show that the majority of the respondents have been in a long term relationship with their partner. The mean duration involved in a relationship for men was about 2.6 years more than that for women (13.1 years and 10.5 years respectively).

In relation to sexual activity male respondents were two times more likely than female respondents to be sexually active (74 and 36 percent respectively). Further exploratory analysis of sexual activity and relationship type (not presented here) showed that 7 percent of males and 3 percent of females of the sexually active population were widowed. This justifies the need for to collect more detailed sexual behaviour data.

The question for the sex practice category attempts to ascertain the respondent's current or past association with a specific group, which in itself might be considered by the society as different, and in some cases morally wrong. This kind of association may be the underlying factor responsible for stigma and discrimination. Majority of the respondents interviewed did not belong to any of the sex categories listed (70 percent). The largest group (10 percent) reported belonging to internally displaced people.

#### **Key Messages: Demographic Characteristics of Respondents**

- There were four times more widows than widowers. However, male respondents were three times more likely than female respondents to be married or cohabiting with a spouse in the same household.
- Majority of the respondents have been in a long term relationship with their partner.
- The mean duration involved in a relationship for men was about 2.6 years more than that for women (13.1 years and 10.5 years respectively).
- The mean duration respondents have been living with HIV was five and a half years. The majority of respondents (64%) reported to have lived with HIV within the last five years.

Education is associated with improved living conditions for people living with HIV. For example, hygiene, nutrition and reproductive behaviour are influenced by educational level. Table 3 shows that majority of the respondents had attained a primary level of education (70 percent). These findings show a similar pattern to that shown in the Rwandan Demographic Health Survey (RDHS) for both men and women who had attained primary education.

Respondents, who reported working full time as self employed and doing casual or part-time work (self-employed) were almost similar (29 and 25 percent respectively). Only three percent of the respondents, reported being in full time employment with an employer.

The mean duration respondents have been living with HIV was five and a half years (Standard Deviation 4; range 1 to 26 years). Furthermore, the percentage distribution of respondents living with HIV peaks at 2-9 years (around 40 percent) and later decreases as numbers follow a convex pattern. The duration living with HIV varies by area: 54 percent in rural areas, 28 percent in villages and 18 percent in cities (not shown in table). Figure 3 shows the distribution of respondents by duration of HIV+ status. The figure shows that the majority of respondents (64.4%) reported to have lived with HIV within the last five years.

**Table 3: Relationship and demographic characteristics of people living with HIV (PLHIV) by sex.**

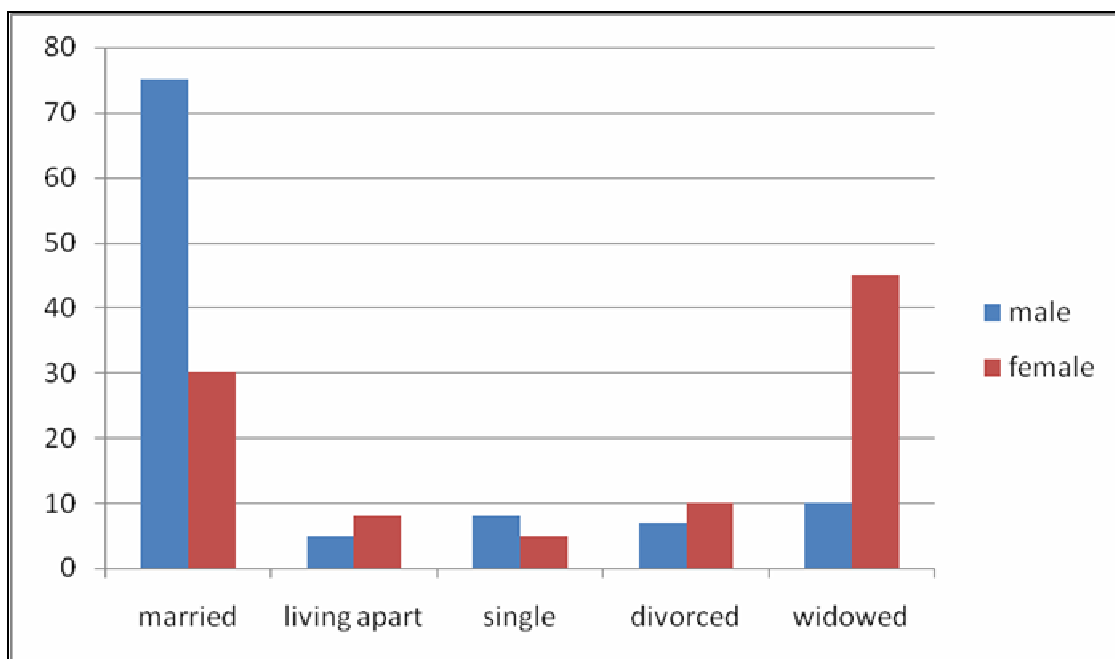
Percentage distribution of current relationship status, current sexual activity, sex practice category of PLHIV by sex, Rwanda 2008.

CHARACTERISTICS	Male	Female	Number	Total
<b>Current relationship status* (N= 1521)</b>				
Married or cohabiting and spouse living in household	76.0	29.8	640	42.1
Married or cohabiting but spouse temporarily living away from household	1.7	3.6	47	3.1
In relationship but not living together	1.5	4.7	58	3.8
Single	5.2	7.3	102	6.7
Divorced/separated	4.7	9.7	127	8.3
Widow/widower	10.9	45.0	547	36.0
<b>Currently Sexually Active* (N= 1539)</b>				
Yes	74.2	35.5	709	46.1
No	25.8	64.5	830	53.9
<b>Sex Practice Category* (N= 1209)</b>				
Men who have sex with men	1.6	1.4	17	1.4
Gay or lesbian	0.0	0.7	6	0.5
Transgender	1.2	0.7	10	0.8
Sex worker	0.6	3.7	35	2.9
Refugee or asylum seeker	6.2	8.9	99	8.2
Internally displaced person	9.3	10.4	122	10.1
Member of indigenous group	0.6	0.8	9	0.7
Migrant worker	8.1	1.9	43	3.6
Prisoner	5.0	0.3	19	1.6
Not belonging to any group	67.4	71.3	849	70.2
<b>Current Employment Status (N = 1444)</b>				
In full-time employment (as an employee)	4.2	2.4	42	2.9
In part-time employment (as an employee)	24.4	22.1	328	22.7
Working full-time but not as an employee (self employed)	30.5	28.5	419	29.0
Doing casual or part-time work (self employed)	21.2	26.3	361	25.0
Unemployed and not working at all	19.6	20.6	294	20.4
<b>Highest Educational Attainment* (N= 1496)</b>				
No formal education	12.2	18.5	252	16.8
Primary school	70.3	70.6	1055	70.5
Secondary school	15.2	10.4	175	11.7
Technical college/university	2.2	0.5	14	0.9
<b>Duration involved with partner * (N= 867)</b>	Male	female	Number	Total
0-1 year	3.2	7.4	50	5.8
2-4 years	13.9	20.6	156	18.0
5-9 years	22.1	22.5	194	22.4
10-14 years	26.5	24.4	219	25.3
15+ years	34.2	25.0	248	28.6

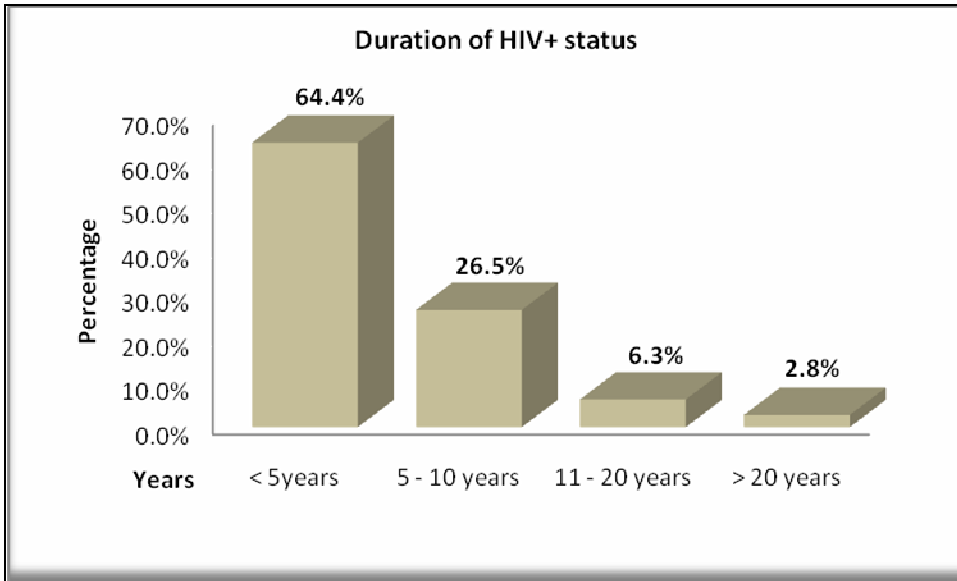
CHARACTERISTICS	Male	Female	Number	Total
Mean duration	13.1	10.5		11.5
<b>Duration living with HIV (N= 1544)</b>				
0-1 year	4.3	5.6	81	5.2
2-4 years	44.7	41.2	650	42.1
5-9 years	39.9	40.1	618	40.0
10-14 years	7.7	8.9	133	8.6
15+ years	3.4	4.2	62	4.0
Mean duration	5.3	5.6		5.5

\* P value < 0.05 statistically significant

**Figure 2: Percentage distribution of respondents by current relationship status and sex, Rwanda 2008**



**Figure 3: Distribution of respondents by duration of HIV+ status, Rwanda 2008**



## SECTION 2: Experience of Stigma and Discrimination

HIV/AIDS-related stigma and discrimination in families and communities is commonly manifested in the form of blame, scape-goating, and punishment. Communities often shun or gossip about those perceived to have HIV or AIDS. In more extreme cases, it has taken the form of violence. The example of Gugu Dlamini, a woman from Durban South Africa, who was stoned in 1998 for publicly declaring her HIV-positive status, is perhaps an extreme illustration of the consequences of disclosure (<http://new.hst.org.za/news/index.php/20010904>). She symbolises the African woman who is stigmatised and discriminated against in subtle and direct ways because of her actual or assumed HIV-positive status.

Section 2 comprises five subsections. The subsections focus on indicators regarding reported experience over the last 12 months, of people living with HIV (PLHIV) and HIV related stigma and discrimination; internal stigma; the protection of the rights of people living with HIV through the law, policy or practice; and effecting change.

### SECTION 2A: Perceived experience of PLHIV of HIV related stigma and discrimination from others over the last 12 months

Stigma refers to a sign of disgrace or shame. Stigma is often described as a process of devaluation. In other words, if one is stigmatised he or she is discredited, seen as a disgrace or perceived to have less value or worth in the eyes of others. This section investigates the perception of stigma and discrimination experienced by people living with HIV (PLHIV) from other people.

The different types of discrimination mentioned were exclusion from social gathering, exclusion from religious activities, exclusion from family activities, frequency of being gossiped about, frequency of being verbally insulted, harassed or being threatened, frequency of being physically harassed, frequency of being physically assaulted, frequency of subjection to psychological pressure or manipulation by your husband/wife/partner, frequency of sexual rejection in the last 12 months, frequency of being discriminated against by other people, frequency of family discriminated against as a result of HIV status.

#### Key Messages: Perceived experience HIV related stigma and discrimination

- Large percentages of respondents reported to have never experienced stigma and discrimination. However, once reported it was more likely to have happened more than once.
- A fewer percentage of respondents reported exclusion from religious activities, followed by exclusion from family activities. More females reported exclusion from family activities and being gossiped about more often than males. This suggests interventions to address stigma and discrimination need to be gender sensitive.
- HIV was the main reason reported for those who felt they experienced discrimination from other people. The discrimination took the form of exclusion from family activities, being gossiped about and physical harassment.



The results presented in Table 4 show the percentage distribution of the perception people living with HIV have towards the way they have been treated in the last 12 months.

It is interesting to observe that a fewer percentage of respondents reported exclusion from religious activities, followed by exclusion from family activities. More females reported exclusion from family activities than males. Similarly, more females reported more frequent occasions being gossiped about. Overall, large percentages of respondents reported never having experienced stigma and discrimination. However, once reported it was more likely to have happened more than once<sup>3</sup>. This suggests that interventions need to be gender sensitive to address stigma and discrimination.

**Table 4: Perceived experience of stigma and discrimination from other people**

Percentage distribution of the perception of people living with HIV has towards the way they have been treated by other people in the last 12 months by sex, Rwanda 2008.

<b>Stigma characteristics</b>	<b>Male</b>	<b>Female</b>	<b>Number</b>	<b>Total</b>
<b>Exclusion from Social Gathering (N= 1502)</b>				
Never	58.8	56.3	855	56.9
Once	8.0	5.3	91	6.1
A few times	17.3	20.2	292	19.4
Often	15.8	18.2	264	17.6
<b>Exclusion from Religious Activities (N= 1343)</b>				
Never	89.2	88.7	1193	88.8
Once	2.3	1.7	25	1.9
A few times	4.1	5.2	66	4.9
Often	4.4	4.4	59	4.4
<b>Exclusion from Family Activities* (N= 1317)</b>				
Never	83.6	76.2	1029	78.1
Once	1.5	1.9	24	1.8
A few times	7.1	10.4	126	9.6
Often	7.7	11.4	138	10.5
<b>Frequency of Being Gossiped* (N= 1344)</b>				
Never	62.1	56.0	774	57.6
Once	2.5	3.7	46	3.4
A few times	15.8	14.0	195	14.5
Often	19.5	26.3	329	24.5
<b>Frequency of being verbally Insulted, harassed or being threatened* (N= 1398)</b>				
Never	53.1	44.2	651	46.6
Once	5.1	6.7	88	6.3
A few times	20.1	19.9	279	20.0
Often	21.7	29.2	380	27.2

<sup>3</sup> It is a concern that high percentage of respondents reported being gossiped about few times and often. This needs further investigation.

<b>Stigma characteristics</b>	<b>Male</b>	<b>Female</b>	<b>Number</b>	<b>Total</b>
<b>Frequency of being Physically Harassed (N= 1385)</b>				
Never	67.8	61.8	878	63.4
Once	5.2	4.8	68	4.9
A few times	12.3	15.2	200	14.4
Often	14.8	18.2	239	17.3
<b>Frequency of being Physically assaulted (N= 1333)</b>				
Never	82.2	79.1	1065	79.9
Once	8.2	7.1	98	7.4
A few times	5.5	7.3	91	6.8
Often	4.1	6.6	79	5.9
<b>Frequency of subjection to psychological pressure or manipulation by your husband/wife/partner (N= 1193)</b>				
Never	74.2	74.6	889	74.5
Once	4.7	2.5	37	3.1
A few times	12.8	11.6	142	11.9
Often	8.3	11.3	125	10.5
<b>Frequency of sexual rejection in the last 12 months* (N= 1351)</b>				
Never	72.4	75.9	1012	74.9
Once	2.9	2.6	36	2.7
A few times	12.1	7.4	118	8.7
Often	12.6	14.1	185	13.7
<b>Frequency of being discriminated against by other people (N= 1463)</b>				
Never	88.2	88.8	1297	88.7
Once	2.3	2.1	31	2.1
A few times	6.2	3.8	65	4.4
Often	3.3	5.3	70	4.8
<b>Frequency of family discriminated as a result of HIV status (N= 1464)</b>				
Never	79.6	73.8	1103	75.3
Once	2.6	3.2	45	3.1
A few times	8.3	9.6	135	9.2
Often	9.6	13.4	181	12.4

\* P value < 0.05 statistically significant

Those who reported that they felt that they were experiencing discrimination from other people were asked the reason why they felt they were discriminated against. Table 5 presents the percentage distribution of the reasons respondents felt they had been stigmatised /discriminated against by other people.

HIV was the leading reason reported for being stigmatised and discriminated against. The highest percentage of respondents reported experiencing exclusion from family activities (82 percent), followed by being gossiped about (71 percent), and physically harassed (70 percent). Physical

assault because of HIV status was the least reported (45 percent). In addition, 47 percent reported being physically assaulted by husband/wife/partner.

Respondents were also asked reasons for being stigmatised and discriminated against because of reasons other than HIV positive status were because they were internally displaced (10 percent) and sex worker (5 percent). Females were more discriminated against than males except for prisoners (5.7 percent males and 0.7 percent females).

**Table 5: Reasons for stigma and discrimination from other people**

Percentage distribution of the reasons respondents felt they had been stigmatized / discriminated against by other people by sex, Rwanda 2008.

<b>Reasons for discrimination and its nature</b>	<b>Male</b>	<b>Female</b>	<b>Number</b>	<b>Total</b>
<b>Reasons for Exclusion from Social Gathering (N= 110)</b>				
Because of HIV status	69.2	69.0	76	69.1
For another reason	7.7	4.8	6	5.5
Both because of your HIV status and other reason	11.5	17.9	18	16.4
No sure why	11.5	8.3	10	9.1
<b>Reasons for Exclusion from Religious Activities (N= 121)</b>				
Because of HIV status	66.7	64.9	79	65.3
For another reason	14.8	6.4	10	8.3
Both because of your HIV status and other reason	11.1	21.3	23	19.0
No sure why	7.4	7.4	9	7.4
<b>Reasons for Exclusion from Family Activities (N= 245)</b>				
Because of HIV status	80.9	82.3	201	82.0
For another reason	6.4	3.0	9	3.7
Both because of your HIV status and other reason	8.5	11.1	26	10.6
No sure why	4.3	3.5	9	3.7
<b>Reasons for being Gossiped At (N= 488)</b>				
Because of HIV status	70.1	72.2	350	71.7
For another reason	12.0	8.1	44	9.0
Both because of your HIV status and other reason	10.3	13.5	62	12.7
No sure why	7.7	6.2	32	6.6
<b>Reasons for being verbally Insulted, harassed or being threatened (N= 654)</b>				
Because of HIV status	71.9	68.9	455	69.6
For another reason	8.5	8.2	54	8.3
Both because of your HIV status and other reason	13.1	15.4	97	14.8
No sure why	6.5	7.6	48	7.3
<b>Reasons for being Physically harassed (N= 421)</b>				
Because of HIV status	76.2	68.4	296	70.3
For another reason	6.7	7.3	30	7.1
Both because of your HIV status and other reason	14.3	21.2	82	19.5
No sure why	2.9	3.2	13	3.1
<b>Reasons for being Physically assaulted (N= 67)</b>				
Because of HIV status	21.4	50.9	30	44.8
For another reason	28.6	22.6	16	23.9

Reasons for discrimination and its nature	Male	Female	Number	Total
Both because of your HIV status and other reason	35.7	11.3	11	16.4
No sure why	14.3	15.1	10	14.9
<b>Person who Physically assaulted you* (N= 227)</b>				
My husband/wife/partner	24.4	52.2	106	46.7
Another member of the household	22.2	19.2	45	19.8
Person outside the household who is/are known to me	31.1	18.7	48	21.1
Unknown person(s)	22.2	9.9	28	12.3
<b>Frequency of being stigmatized or discriminated at due to reasons other than HIV* (N= 834 )</b>				
Sexual orientation(men having sex with men, gay or lesbian, transgender	3.5	1.6	18	2.2
Sex worker	4.0	5.3	41	4.9
Injecting drug user	0.4	1.2	8	1.0
Refugee or asylum seeker	3.1	3.0	25	3.0
Internally displaced person	7.5	10.4	80	9.6
Member of an indigenous group	1.8	2.0	16	1.9
Migrant worker	1.3	1.8	14	1.7
Prisoner	5.7	0.7	17	2.0
None of the above	72.7	74.1	615	73.7

\* P value < 0.05 statistically significant

## SECTION 2B: Access to work and health and education services

This section tries to examine whether the interviewee perceives that their access to work (and in some cases the access of members of their household) and to basic services such as health and education has been limited or reduced because of their HIV-positive status.

Table 6 shows the percentage distribution of PLHIV perceived experience on access to work and health and education by sex.

Unlike in the previous chapter on perceived stigma and discrimination, here, large percentages of respondents reported being denied access to work, health and education services. Although, 87 percent of the respondents reported they had never been denied health services, it is surprising that 88 percent of respondents reported being denied family planning services because of their HIV positive status in the last 12 months. On the contrary only 13 percent reported being denied sexual reproductive health services.

### Key Messages: Access to social services

- Although 87 percent of the respondents reported that they had never been denied health services, a large percentage (88 percent) of respondents reported being denied family planning services because of their HIV positive status in the last 12 months.
- HIV-positive status was the major reason reported for denial or refusal of access accommodation, work, health and educational services.



**Table 6: Experience with access to work and health and education services**

Percentage distribution of PLHIV reported being denied access to work and health and education in the last 12 months by sex, Rwanda 2008.

CHARACTERISTICS	Male	Female	Number	Total
<b>Frequency of changing place of resident or unable to rent accommodation by force (N= 1471)</b>				
Never	62.9	62.6	922	62.7
Once	7.4	6.1	95	6.5
A few times	12.0	10.8	164	11.1
Often	17.6	20.5	290	19.7
<b>Frequency of loss of job or other source of income (self employed, informal/loss casual work) (N= 1465)</b>				
Never	38.2	33.6	510	34.8
Once	4.2	4.9	69	4.7
A few times	29.3	33.5	475	32.4
Often	28.3	28.0	411	28.1
<b>Frequency of employment opportunity refused because of HIV status in the last 12 months (N= 1457)</b>				
Yes	41.3	35.7	542	37.2
No	58.7	64.3	915	62.8
<b>Frequency of changing job description/nature of work and refusal of promotion (N= 1404)</b>				
Never	70.6	73.0	1016	72.4
Once	5.8	3.8	61	4.3
A few times	10.7	11.8	162	11.5
Often	12.9	11.3	165	11.8
<b>Frequency of dismissal or suspension and deprivation for attending educational institute (N= 1417)</b>				
Never	65.6	61.7	888	62.7
Once	1.4	1.6	22	1.6
A few times	2.8	1.7	28	2.0
Often	5.0	5.7	78	5.5
Not applicable	25.3	29.3	401	28.3
<b>Frequency of dismissal or suspension and deprivation of child/children for attending educational institute (N= 1448)</b>				
Never	80.2	75.0	1106	76.4
Once	2.9	1.6	28	1.9
A few times	4.2	5.5	75	5.2
Often	5.6	8.0	107	7.4
Not applicable	7.1	9.8	132	9.1
<b>Frequency of being denied health services, including dental care (N= 1461)</b>				
Never	87.9	86.9	1287	87.2
Once	2.1	1.9	29	2.0
A few times	3.4	2.1	36	2.4
Often	2.8	4.3	58	3.9

Not applicable	3.9	4.7	51	4.5
<b>Ever being denied family planning services (N= 1424)</b>				
Yes	91.1	86.6	1250	87.8
No	7.5	11.7	151	10.6
Not applicable	1.3	1.7	23	1.6
<b>Ever being denied sexual and reproductive health services (N= 1455)</b>				
Yes	13.0	12.9	188	12.9
No	87.0	87.1	1267	87.1

Respondents who reported ever being denied services were asked the reason for discrimination. Table 7 shows percentage distribution of the reasons for denial/refusal to access to work and selected services by sex. There was a statistically significant difference by respondents' category who reported changing place of residence or unable to rent accommodation by force.

HIV-positive status was the major reason reported for denial or refusal of access accommodation, work, health and educational services. An exception was those who lost job or income because of HIV-positive status reported that they felt obliged to stop working due to poor health (66 percent).

**Table 7: Reasons for denial/refusal to access work and health and education services**

Percentage distribution of the reasons for denial/refusal to access to work and health and education services in the last 12 months by sex, Rwanda 2008.

CHARACTERISTICS	Male	Female	Number	Total
<b>Reasons for changing place of residence or unable to rent accommodation by force * (N= 470)</b>				
Because of HIV status	41.3	33.1	166	35.3
For another reason	36.5	31.7	155	33.0
Both because of your HIV status and other reason	19.0	27.6	119	25.3
No sure why	3.2	7.6	30	6.4
<b>Reasons for loss of job or other source of income (self employed, informal/casual worker) in the last 12 months (N= 811)</b>				
Because of HIV status	43.4	37.8	318	39.2
For another reason	28.3	25.7	214	26.4
Both because of your HIV status and other reason	23.4	31.5	239	29.5
No sure why	4.9	5.0	40	4.9
<b>Lost job/income due to HIV status because of (N= 300)</b>				
Because of discrimination by employer/co-worker	21.2	14.0	48	16.0
Because you felt obliged to stop working due to poor health	57.6	69.3	198	66.0
Because of combination of discrimination and poor health	12.9	13.0	39	13.0
Because of another reason	8.2	3.7	15	5.0

\* P value < 0.05 statistically significant

## SECTION 2C: Internal stigma and fears

According to the Stigma Index Guide, internal stigma also referred to as “felt” stigma or “self stigmatisation” is used to describe the way a person living with HIV feels about themselves and specifically if they feel a sense of shame about being HIV-positive. Internal stigma (felt stigma or self stigmatisation) can lead to low self-esteem, a sense of worthlessness and depression among people living with HIV. Internal stigma can also result in a person living with HIV withdrawing from social and intimate contact, or excluding themselves from accessing services and opportunities out of a fear of having their status revealed or being discriminated against because of their HIV status.

Table 8 shows the percentage distribution of the perception and fears respondents had as a result of their HIV-positive status by sex. Questions asked centred on whether the respondent felt ashamed, guilty, blamed themselves, blamed others, had low self esteem, felt they were being punished, and felt suicidal. Self blame because of HIV, blaming of others, and low self-esteem showed a statistically significant difference by sex.

The majority of the respondents reported that they felt ashamed because of their HIV status (45 percent). Feeling of guilt (27 percent), self blame (25 percent), low self-esteem (22 percent), and the blaming of others (21 percent) were among the leading forms of internal stigma. Eleven percent reported feeling that they should be punished. There were more female respondents than males who expressed negative feelings of stigma and discrimination.

### **Key Messages: Internal stigma and fears**

- Forty five percent of respondents reported that they felt ashamed because of their HIV status. The main forms of internal stigma were feelings of guilt, self-blame and low self esteem.
- About three-quarters of the respondents decided not to have more children and about half of them decided not to have sex as a result of their HIV-positive status.
- Anticipation of fear of being gossiped, verbally insulted, harassed and/or threatened was higher for females, while more men feared that someone would not want to be sexually intimate with them because of HIV infection.

**Table 8: Internal stigma (feelings and fears) as a result of HIV-positive status**

Percentage distribution of perception and fears respondents had had for themselves as a result of their HIV-positive status by sex, Rwanda 2008.

Feelings	Sex			
	Male	Female	Number	Total
<b>Ashamed (N= 1189)</b>				
Yes	41.2	46.4	536	45.1
No	58.8	53.6	653	54.9
<b>Guilty (N= 1069)</b>				
Yes	24.5	27.1	283	26.5
No	75.5	72.9	786	73.5
<b>Self blame * (N= 1123)</b>				
Yes	20.1	26.1	275	24.5
No	79.9	73.9	848	75.5
<b>Blame others * (N= 1100)</b>				



Feelings	Sex			
	Male	Female	Number	Total
Yes	11.5	24.1	229	20.8
No	88.5	75.9	871	79.2
<b>Low self esteem * (N= 1111)</b>				
Yes	17.4	23.3	242	21.8
No	82.6	76.7	869	78.2
<b>Feel should be punished (N= 1070)</b>				
Yes	11.1	10.5	114	10.5
No	88.9	89.5	956	89.3
<b>Suicidal (N= 1135)</b>				
Yes	10.6	15.1	158	13.9
No	89.4	84.9	977	86.1

\* P value < 0.05 statistically significant

Table 9 shows the percent distribution of respondent's decision not to engage in some activities because of their HIV positive status by sex. Questions on relations, education, career, and health services were asked. There was a statistically significant difference by sex for decision to withdraw from education/training or not taking up an opportunity for education/training because of HIV status and decision not to have sex because of HIV status in the last 12 months.

About three-quarter of the respondents decided not to have more children as a result of their HIV-positive status. Although, 71 percent of the respondents had the intention of getting married, about half the respondents (49.6 percent of 551) decided not to have sex because of their HIV-positive status. Fewer respondents decided to stop working because of their HIV status.

**Table 9: Decision not to engage in some activities because of HIV status**

Percent distribution of respondent's decision not to engage in some activities because of HIV status in the last 12 months by sex, Rwanda 2008.

Decision taken	Male	Female	Number	Total
<b>Chosen not to attend social gatherings (N= 1117)</b>				
Yes	13.7	15.1	165	14.8
No	86.3	84.9	952	85.2
<b>Isolated self from the family and/or friends (N= 1052)</b>				
Yes	8.0	8.1	85	8.1
No	92.0	91.9	967	91.9
<b>Took decision to stop working (N= 1004)</b>				
Yes	6.4	4.7	52	5.2
No	93.6	95.3	952	94.8
<b>Decision not to apply for a job/work or for a promotion (N= 930)</b>				
Yes	6.0	5.3	51	5.5
No	94.0	94.7	879	94.5

Decision taken	Male	Female	Number	Total
<b>Decision to withdraw from education/training or not taking up an opportunity for education/training * (N= 886)</b>				
Yes	6.9	7.7	66	7.4
No	93.1	92.3	820	92.6
<b>Decision not to get married (N= 968)</b>				
Yes	16.0	33.4	280	28.9
No	84.0	66.6	688	71.1
<b>Decision not to have sex * (N= 1112)</b>				
Yes	34.0	54.8	551	49.6
No	66.0	45.2	561	50.4
<b>Decision not to have (more) children (N= 1215)</b>				
Yes	70.6	75.6	902	74.2
No	29.4	24.4	313	25.8
<b>Decision to avoid needed local clinic visit (N= 1003)</b>				
Yes	10.5	10.3	104	10.4
No	89.5	89.7	899	89.6
<b>Decision to avoid needed hospital visit (N= 1016)</b>				
Yes	5.9	8.2	77	7.6
No	94.1	91.8	939	92.4

\* P value < 0.05 statistically significant

The percent distribution of anticipation for fear of being gossiped about, verbally insulted, harassed and /or threatened, physically harassed, and physically assaulted by sex is shown in Table 10. There was a statistically significant difference by sex for fear of being harassed.

In general, a high percentage of respondents said they anticipated fear of being gossiped about, being verbally insulted, harassed and/or threatened, and fear that someone would not want to be sexually intimate with them because of their HIV status (49 percent, 42 percent, and 43 percent respectively). About one in five respondents had fear of being physically assaulted. Anticipation of fear was higher for females, except fear that someone would not want to be sexually intimate with them.

**Table 10: Fear of having negative events happening because of HIV by sex.**

Percent distribution of fear of being gossiped, verbally insulted, harassed and /or threatened, physically harassed, and physically assaulted by sex, Rwanda 2008.

Types of Fear	Sex		Number	Total
	Male	Female		
<b>Fear of being gossiped about (N= 1274)</b>				
Yes	46.6	49.8	624	49.0
No	53.4	50.2	650	51.0
<b>Fear of being verbally insulted, harassed and/or threatened (N= 1116)</b>				
Yes	37.7	43.8	470	42.1

Types of Fear	Sex			
No	62.3	56.2	646	57.9
<b>Fear of being physically harassed and/or threatened (N= 1087)</b>				
Yes	32.4	37.3	391	36.0
No	67.6	62.7	696	64.0
<b>Fear of being physically assaulted* (N= 1008)</b>				
Yes	15.2	23.7	216	21.4
No	84.8	76.3	792	78.6
<b>Fear that someone would not want to be sexually intimate with you because of your HIV status (N= 1349)</b>				
Yes	47.3	40.9	575	42.6
No	52.7	59.1	774	57.4

\* P value < 0.05 statistically significant

## SECTION 2D: Rights, Laws and Policies

This section focuses on the awareness of the international agreement from 2001 called the Declaration of Commitment on HIV. In the declaration, governments affirmed that the realisation of human rights and fundamental freedoms for all is essential to reduce vulnerability to HIV. Human rights are legally guaranteed by human rights law, which exist to protect individuals and groups from actions that interfere with their freedom and dignity, and promote access to the things that help people realise their rights. Human rights law exist at the international level (e.g. treaties and covenants) and at the national level (e.g. constitution, bill of rights, domestic laws).

The percentage distribution of respondents' knowledge of laws (both international and national) on HIV which protects PLHIV<sup>4</sup>, and laws that addresses the rights for those who are violated by sex is shown in Table 11. The table also shows the types of human rights violations experienced by respondents: being detained, quarantined, isolated or segregated because of HIV+ status in the last 12 months showed a statistically significant difference by sex.

Over 50 percent of the respondents reported that they had heard of the Declaration of Commitment on HIV/AIDS which protects the rights of people living with HIV. Only slightly above one-quarter of the respondents reported that they had knowledge of the Rwandan law which protects rights of PLHIV.

<sup>4</sup> During training the research team was not aware of any local laws directly impacting on human rights for PLHIV, we decided to include the questions for survey participants.

More than half (53 percent) reported experiencing some form of discrimination. It is a concern that about 18 percent reported being forced to submit to a medical or health procedure (including HIV testing), and ten percent have been denied health insurance because of their HIV+ status. At least two percent have been arrested or taken to court on a charge related to HIV status. Although fewer than five percent of the respondents had been arrested, or forced to disclose HIV status during travel in the last 12 months. However, these percentages are in no way insignificant and need further investigation.

**Key Messages: Rights, laws and policies**

- More than half of the respondents reported they had heard of the Declaration of Commitment on HIV/AIDS which protects the rights of people living with HIV.
- It is a concern that about 18 percent have been forced to submit to a medical or health procedure (including HIV testing), and ten percent have been denied health insurance because of their HIV+ status.

**Table 11: Knowledge of rights, laws and policies**

Percent distribution of respondent's knowledge of laws (both international and national) on HIV which protect PLHIV, and having had rights violated in the last 12 months by sex, Rwanda 2008.

Experience with laws	Sex		Number	Total
	Male	Female		
<b>Heard of the Declaration of Commitment on HIV/AIDS which protects the rights of people living with HIV (N= 1527)</b>				
Yes	54.5	52.7	812	53.2
No	45.5	47.3	715	46.8
<b>Have knowledge of a Rwandan law which protects the rights of PLHIV (N= 1386)</b>				
Yes	28.0	27.7	385	27.8
No	72.0	72.3	1001	72.2
<b>Have been forced to submit to a medical or health procedure ( including HIV testing), in the last 12 months (N= 1595)</b>				
Yes	19.7	16.8	280	17.6
No	80.3	83.2	1315	82.4
<b>Have been denied health insurance because of HIV+ status in the last 12 month (N= 1595)</b>				
Yes	9.6	9.4	151	9.5
No	90.4	90.6	1444	90.5
<b>Have been arrested or taken to court on a charge related to HIV status (N= 1595)</b>				
Yes	1.4	1.5	24	1.5
No	98.6	98.5	1571	98.5
<b>Have to disclose the HIV status in order to enter another country (N= 1595)</b>				
Yes	4.0	4.5	70	4.4

No	96.0	95.5	1525	95.6
<b>Have to disclose the HIV status to apply for residence or nationality, (N= 1595)</b>				
Yes	0.5	0.7	10	0.6
No	99.5	99.3	1585	99.4
<b>Have been detained, quarantined, isolated or segregated* (N= 1595)</b>				
Yes	1.6	5.0	65	4.1
No	98.4	95.0	1530	95.9
<b>Nothing of the above happened (N= 1595)</b>				
Yes	48.7	46.2	748	46.9
No	51.3	53.8	847	53.1

\* P value < 0.05 statistically significant

Table 12 shows percentage distribution of respondents who reported abuse of rights of PLHIV and of being taken to legal redress by sex.

About 31 percent interviewed reported that they have had their rights abused due to their HIV-positive status. One third (33 percent) of the respondents said they got a government employee to take action against an abuse of rights, and 88 percent of 271 respondents<sup>5</sup> who reported getting a government employee to take action against an abuse of rights did it in the last 12 months (there were 53 non-responses). Conversely, 31 percent of 784 respondents (applicable cases) said they got a local or national politician to take action against an abuse of rights. Majority (85 percent) of the 208 respondents interviewed got a local or national politician to take action against an abuse of PLHIV rights in the last 12 months. Majority of the respondents (42 percent) reported that the matter had been dealt with.

**Table 12: Abuse of PLHIV rights and action taken**

Percent distribution of respondents reporting experience of abuse of rights and action taken by sex, Rwanda 2008.

Human rights and action	Male	Female	Number	Total
<b>Have had PLHIV rights abused (N= 1454)</b>				
Yes	31.8	31.3	457	31.4
No	68.2	68.5	995	68.4
Not sure	0.0	0.2	2	0.1
<b>Got a government employee(s) to take action against an abuse of PLHIV rights (N= 815)</b>				
Yes	33.5	33.2	271	33.3
No	66.5	66.8	544	66.7
<b>Got a government employee(s) to take action against an abuse of PLHIV rights as a person in the last 12 months (N= 218)</b>				
Yes	88.3	87.3	191	87.6
No	11.7	12.7	27	12.4

<sup>5</sup> Only applicable cases and 63 missing values

Human rights and action	Male	Female	Number	Total
<b>Results of getting a government employee(s) to take action against an abuse of PLHIV rights (N= 211)</b>				
The matter has been dealt with	36.0	34.8	74	35.1
The matter is still in the process of been dealt with	24.0	26.1	54	25.6
Nothing happened, the matter was not dealt with	40.0	39.1	83	39.3
<b>Got a local or national politician to take action against an abuse of rights of PLHIV (N= 784)</b>				
Yes	27.1	31.7	239	30.5
No	72.9	68.3	545	69.5
<b>Got a local or national politician to take action against an abuse of rights of PLHIV in the last 12 months (N= 208)</b>				
Yes	87.5	83.8	176	84.6
No	12.5	16.3	32	15.4
<b>Result of getting a local or national politician to take action against an abuse of rights of PLHIV (N= 192)</b>				
The matter has been dealt with	46.9	40.6	81	42.2
The matter is still in the process of been dealt with	18.4	18.2	35	18.2
Nothing happened, the matter was not dealt with	34.7	41.3	76	39.6

The percentage distribution of PLHIV, who have discussed the content of the declaration, got and begun legal redress for any abuse of rights, and the result of the process by sex, is shown in Table 13. There was a statistically significant difference by sex for respondents who read or discussed content of the declaration.

About two-thirds of the respondents interviewed have read or discussed content of the declaration of commitment on HIV and AIDS which protects the rights of PLHIV. However, there was no significant difference between those who got a legal redress and those who did not. Forty percent reported these matters had been dealt with. Majority (24 percent) of those who did not get a legal redress said that the process of addressing the problem appeared too bureaucratic, followed by insufficient financial resources to take action.

**Table 13: PLHIV who have addressed legal matters relating to stigma and discrimination by sex**  
Percentage distribution of PLHIV, who have discussed the content of the declaration, got legal redress for any abuse of rights, legal redress begun, and result of the process by sex, Rwanda 2008.

CHARACTERISTICS	Male	Female	Number	Total
<b>Have read or discussed content of the declaration* (N= 764)</b>				

Yes	73.1	63.6	506	66.2
No	26.9	36.4	258	33.8
<b>Got legal redress for any abuse of rights of PLHIV (N= 357)</b>				
Yes	40.8	46.7	161	45.1
No	45.9	45.2	162	45.4
Not sure	13.3	8.1	34	9.5
<b>Legal process begun in the last 12 months (N= 192)</b>				
Yes	93.8	84.7	167	87.0
No	6.2	15.3	25	13.0
<b>Result of the process (N= 217)</b>				
The matter has been dealt with	32.2	42.4	86	39.6
The matter is still in the process of being dealt with	25.4	22.8	51	23.5
Nothing happened, the matter was not dealt with	42.4	34.8	80	36.9
<b>Reason for not trying to get legal redress (N= 221)</b>				
Insufficient financial resources to take action	29.2	19.9	50	22.6
Process of addressing the problem appeared too bureaucratic	20.0	26.3	54	24.4
Felt intimidated or scared to take action	3.1	3.2	7	3.2
Advised against taking legal action by someone else	1.5	3.8	7	3.2
No/little confidence that outcome would be successful	7.7	6.4	15	6.8
No reason for not trying to get legal redress	38.5	40.4	88	39.8

\* P value < 0.05 statistically significant

## SECTION 2E: Effecting change

This section focuses on actions or what one does in order to bring about positive change. Respondents were asked to describe some actions that they might have taken in attempting to resolve or challenge an incident of HIV-related stigma and discrimination, and make recommendations for organisations working against stigma and discrimination.

Table 14 shows the percentage distribution of some actions taken by respondents in order to resolve or challenge an incident of HIV-related stigma and discrimination. There was a statistically significant difference by sex for respondents who reported supporting other people living with HIV.

About half of the respondents have confronted someone discriminating against them, and knew organisations or groups where they can go for help on experiencing stigma or discrimination. Over 80 percent of respondents reported supporting other people living with HIV, mostly emotional support (92 percent), physical support (74 percent), and less in terms of referral to other services (39 percent) was reported as a form of support rendered. In terms of involvement, around 45 percent had been involved in project activities and policies related to PLHIV.

### **Key Messages: Effecting change**

- About half of the respondents have confronted someone discriminating against them, and knew organisations or groups where they can go for help when experiencing stigma or discrimination.
- Over 80 percent of respondents reported supporting other people living with HIV in terms of emotional and physical support.
- There was low knowledge of organisations that help care for people living with HIV. The most widely known organisations were networks of people living with HIV.
- Only about a quarter of respondents reported that they felt they had influence in decision making in policies and programmes locally and wider.

**Table 14: Effecting change**

Percentage distribution of some action taken by respondents in an attempt to resolve or challenge an incident of HIV-related stigma and discrimination by sex, Rwanda 2008.

Action effected	Male	Female	Number	Total
<b>Have you confronted/challenged or educated someone who was stigmatizing and/or discriminating against you? (N= 1476)</b>				
Yes	49.6	50.2	739	50.1
No	50.4	49.8	737	49.9
<b>Do you know of any organisation or groups that you can go to for help if you experience stigma or discrimination? (N= 1484)</b>				
Yes	51.9	47.9	727	49.0
No	48.1	52.1	757	51.0
<b>In the last 12 months have you supported other people living with HIV* (N= 1447)</b>				
Yes	80.4	84.8	1211	83.7
No	19.6	15.2	236	16.3
<b>If YES what type of support?</b>				



Action effected	Male	Female	Number	Total
<b>Emotional support (e.g. counselling, sharing personal stories and experience) (N= 1118)</b>				
Yes	91.1	92.4	1029	92.0
No	8.9	7.6	89	8.0
<b>Physical support (e.g. providing money or food, doing an errand for them) (N= 1158)</b>				
Yes	74.5	73.1	851	73.5
No	25.5	26.9	307	26.5
<b>Referral to other services (N= 1521)</b>				
Yes	38.3	39.6	597	39.3
No	61.7	60.4	924	60.7
<b>Are you currently a member of people living with HIV support group and/ or network? (N= 1468)</b>				
Yes	89	85.2	1265	86.2
No	11	14.8	203	13.8
<b>In the last 12months have you been involved either as a volunteer or as an employee in any programme or project that provides assistance to PLHIV? (N= 1410)</b>				
Yes	46.8	42.3	613	43.5
No	53.2	57.7	797	56.5
<b>In the last 12 months have you been involved in any efforts to develop legislation, policies or guidelines related to HIV? (N= 1462)</b>				
Yes	47.0	45.7	673	46.0
No	53.0	54.3	789	54.0

Table 15 shows the percentage distribution of respondents by knowledge of different types of organisations or groups that one can go for help if stigma and discrimination is experienced. There was a statistically significant difference by sex for respondents who reported they knew a local non-governmental organisation, legal practice, and an international non-governmental organisation they can go for help if they experienced stigma and discrimination.

More than half of the respondents reported that they do not know an organisation or groups that care for people living with HIV. Among the few that knew an organisation that care for people living with HIV, networks of people living with HIV (40 percent) was highly reported, followed by people living with HIV support groups. Only 10 percent reported they knew faith based organisations where they could go for help.

**Table 15: Knowledge of an organisation/groups by sex**

Percentage distribution of respondents by knowledge of an organisation/ groups that care for people living with HIV by sex, Rwanda 2008. (N=1595)

Organisation type	Male	Female	Number	Total
<b>People living with HIV support group</b>				
Yes	28.6	28.3	454	28.4
No	71.4	71.7	1141	71.6
<b>Network of people living with HIV</b>				
Yes	40.0	40.2	640	40.1
No	60.0	59.8	955	59.9
<b>Local non-governmental organisation*</b>				
Yes	10.3	6.6	121	7.6
No	89.7	93.4	1474	92.4
<b>Faith-based organisation</b>				
Yes	10.8	10.2	165	10.3
No	89.2	89.8	1430	89.7
<b>A legal practice*</b>				
Yes	6.3	3.4	67	4.2
No	93.7	96.6	1528	95.8
<b>A human rights organisation</b>				
Yes	13.3	10.5	180	11.3
No	86.7	89.5	1415	88.7
<b>National non-governmental organisation</b>				
Yes	6.1	4.2	75	4.7
No	93.9	95.8	1520	95.3
<b>National AIDS council or committee</b>				
Yes	28.6	26.4	430	27.0
No	71.4	73.6	1165	73.0
<b>International non-governmental organisation*</b>				
Yes	7.7	4.7	88	5.5
No	92.3	95.3	1507	94.5
<b>UN organisations</b>				
Yes	0.9	1.5	21	1.3
No	99.1	98.5	1574	98.7

The percentage distribution of respondents who felt they have or have no power to influence decisions in policies and programmes is shown in Table 16.

About one in every four respondents reported that they have influence on decision making. Slightly above one-quarter reported that they have influence on local projects intended to benefit people

living with HIV. Less than 10 percent felt that they have influence on international agreement and treaties.

**Table 16: Power to influence decisions in policies and programmes by sex**

Percentage distribution of respondents who felt they have or have no power to influence decisions in policies and programmes by sex, Rwanda 2008. (N= 1595)

<b>Policies and programmes</b>	<b>Male</b>	<b>Female</b>	<b>Number</b>	<b>Total</b>
<b>Legal /rights matters affecting people living with HIV</b>				
Yes	15.2	15.2	242	15.2
No	84.8	84.8	1353	84.8
<b>Local government policies affecting people living with HIV</b>				
Yes	23.0	21.7	352	22.1
No	77.0	78.3	1243	77.9
<b>Local projects intended to benefit people living with HIV</b>				
Yes	27.2	27.3	435	27.3
No	72.8	72.7	1160	72.7
<b>National government policies affecting people living with HIV</b>				
Yes	20.4	18.8	307	19.2
No	79.6	81.2	1288	80.8
<b>National programmes/projects intended to benefit people living with HIV</b>				
Yes	22.2	22.9	362	22.7
No	77.8	77.1	1233	77.3
<b>International agreement and treaties</b>				
Yes	9.6	9.8	156	9.8
No	90.4	90.2	1439	90.2
<b>None of the above (N= 1593)</b>				
Yes	30.8	28.7	466	29.3
No	69.2	71.3	1127	70.7

Table 17 shows the percentage distribution of the respondents' most important recommendations to address stigma and discrimination.

More than one-third of the respondents recommended that organisations of people living with HIV working against stigma and discrimination should advocate for the rights of all people living with HIV, followed by providing support for people living with HIV (21 percent), and educating people living with HIV about living with HIV (19 percent).

**Table 17: Recommendations to address stigma and discrimination by sex**

Percentage distribution of the recommendations suggested by people living with HIV to address stigma and recommendation by sex, Rwanda 2008. N=907

Recommendations	Male	Female	Number	Total
Advocating for the rights of all people living with HIV	40.6	38.1	352	38.8
Providing support to PLHIV by providing support	18.5	21.9	190	20.9
Advocating for right & providing support to particular groups	10.6	7.7	77	8.5
Educating PLHIV about living with HIV	18.5	19.0	171	18.9
Raising the awareness & knowledge of public about AIDS	11.8	13.3	117	12.9

## SECTION 3: Experience of Testing, Disclosure, Treatment and having Children.

This section comprises five sub-sections which deal with testing and diagnosis, disclosure and confidentiality, treatment, interviewee's experience of having children, and problems and challenges encountered in relation to them. HIV testing plays an important role in the diagnosis of HIV. Universal access to diagnosis and treatment of HIV can advance public health goals of HIV control, prevention, and education.

### SECTION 3A: Testing and diagnosis

Table 18 shows the percentage distribution of people living with HIV who tested for HIV by various reasons related to relationships and health. Apart from testing for other reasons, testing because of pregnancy, illness and death of husband/wife/partner/family member showed a statistically significant difference by sex. For those who tested for HIV because of pregnancy; the percentage for females was more than twice that of males that tested for HIV because of pregnancy related reasons. Importantly, males who tested for HIV because of pregnancy related reasons may be an opportunity for male involvement in reproductive health issues<sup>6</sup>. 'Triggered by pregnancy' is evidence of unprotected sex, as is death, which may be too late. Therefore there is a need to promote testing before entering sexual relationships. Partner/family member (14 percent) was among the leading cause why PLHIV tested for HIV. However, only four percent of the respondents tested in order to prepare for marriage/sexual relationship. This is a concern, especially since testing is a major intervention for HIV prevention and AIDS treatment.

#### **Key Messages: Testing and diagnosis:**

- Majority undergo HIV testing because of pregnancy. The data for both males and females suggest that the woman's pregnancy triggered both partners to test. This poses an opportunity for male involvement in reproductive health issues.
- A low four percent of the respondents tested to prepare for marriage/sexual relationship.
- The majority of respondents made a decision to test on their own, and they availed themselves of both pre- and post-HIV test counselling.

<sup>6</sup> This is not surprising since antenatal sentinel survey has been the main means of HIV data collection in Rwanda, and many countries in sub-Saharan Africa.

**Table 18: Testing and Diagnosis, by sex**

Percentage distribution of people living with HIV who tested for HIV by specified reasons by sex, Rwanda 2008. N=1595

Reasons for testing	Male	Female	Number	Total
<b>Employment</b>				
Yes	5.2	3.3	60	3.8
No	94.8	96.7	1535	96.2
<b>Pregnancy *</b>				
Yes	12.2	25.8	353	22.1
No	87.8	74.2	1242	77.9
<b>To prepare for marriage/sexual relationship</b>				
Yes	5.6	3.9	70	4.4
No	94.4	96.1	1525	95.6
<b>Referred by a clinic for sexually transmitted infections</b>				
Yes	5.9	6.6	105	6.6
No	94.1	93.4	1490	93.4
<b>Referred due to suspected HIV- related symptoms (e.g. Tuberculosis)</b>				
Yes	10.1	8.7	145	9.1
No	89.9	91.3	1450	90.9
<b>Husband/wife/partner/family tested positive</b>				
Yes	11.5	6.2	121	7.6
No	88.5	93.8	1474	92.4
<b>Illness or the death of husband/wife/partner/family member *</b>				
Yes	12.2	14.6	223	14.0
No	87.8	85.4	1372	86.0
<b>Other reasons for HIV testing</b>				
Yes	35.8	33.5	544	34.1
No	64.2	66.5	1051	65.9

Decision to test for HIV motivates an individual to make informed choices about where and how to access treatment, care and support, and psychosocial support.

Table 19 shows the percentage distribution of people living with HIV according to the one who made the decision to test for HIV by sex.

More than three quarter of the respondents made a self-decision to be tested, whereas about 13 percent of the respondents made a decision to be tested but under pressure. About one in every 12 respondents tested involuntarily.

**Table 19: Decision to test for HIV by sex**

Percentage distribution of people living with HIV by whose decision it was to test for HIV by sex, Rwanda 2008. (N= 1374)

Testing experience	Male	Female	Number	Total
<b>Self decision to be tested</b>	79.3	78.6	1083	78.8
<b>Take decision to be tested but under pressure</b>	14.1	13.0	183	13.3
<b>Be made to take an HIV test</b>	1.4	1.5	20	1.5
<b>Tested without knowledge found out after the test had been done.</b>	5.2	6.9	88	6.4

Table 20 shows the percentage of distribution of people living with HIV who received counselling when tested for HIV.

Eighty five percent of the respondents reported undergoing both pre- and post-HIV test counselling. Percentage of respondents who reported receiving post-test HIV counselling was more than those who reported receiving pre-test HIV counselling.

**Table 20: Received counselling when tested for HIV by sex**

Percentage distribution of people living with HIV who received counselling when tested for HIV by sex, Rwanda 2008. (N= 1414)

Counselling received	Male	Female	Number	Total
Received both pre and post HIV test counselling	83.7	85.6	1203	85.1
Received only pre test HIV counselling	6.1	4.6	71	5.0
Received only post test HIV counselling	8.9	8.9	126	8.9
Did not receive any HIV counselling when tested for HIV	1.3	0.9	14	1.0

## SECTION 3B: Disclosure and confidentiality

Disclosure of sensitive information is generally thought to have beneficial effects on an individual's health. Disclosure is believed to lower stress levels and ultimately lead to better psychological health (Pennebaker *et al.*, 1990). A certain level of disclosure is necessary to access AIDS-related health care resources (Sowell *et al.*, 2003). HIV-infected individuals who disclose their sero-positive status have been found to make fewer physician visits and have better immune functioning (Pennebaker *et al.*, 1990). Choosing to disclose may result in less social isolation, and facilitate accessing social support, health care and social services (Cline and Boyd, 1993). Disclosure of one's HIV status to sexual partners is essential in stopping the spread of HIV infection (Kalichman and Nachimson, 1999).

Studies on stigma and discrimination have show-cased instances where patients were tested for HIV without prior consent, and as such breaching the confidentiality of the patient. Failure to respect confidentiality by clearly identifying patients with HIV/AIDS, and by revealing sero-status to relatives without prior consent, or releasing information to the media appear to be the problems in some health services. The contributing factor to these stigmatising and discriminatory responses may include lack of knowledge, and perception that caring for PLHIV is pointless because AIDS is incurable.

Table 21 shows the percentage of distribution of respondents by whom they disclosed their HIV-positive status to and the manner in which it was done.

Majority of the respondents self-disclosed their HIV-positive status to family members. Most disclosed to other people living with HIV and health care worker<sup>7</sup>, and social workers (95 percent and 93 percent and 91 percent respectively), and the least percentage to co-workers. Just over two-thirds disclosed to community leaders.

It is interesting to note that a higher percentage of males disclosed to partners than females (88 percent and 77 percent respectively). Equally interesting is that more females disclosed to children in the household than males (84 percent and 77 percent respectively). This may suggest that men may be taking the lead to disclose as heads of the marriage/relationship. It may also suggest

### **Key Messages: Disclosure and confidentiality**

- People are generally supportive of PLHIV, and other PLHIV are the most supportive followed by health care and social workers. This supports the need to implement GIPA principles in all AIDS programming.
- Majority of respondents self-disclosed their HIV+ status to family members. Men disclosed more to partners while women to their children.
- Nearly 60 per cent of respondents reported that they often "felt" pressure to disclose their HIV status from other individuals not living with HIV (e.g. family members, social workers, and NGO employees)
- It is comforting that three-quarters of respondents reported they felt confident medical records are kept confidential.
- Respondents reported a more supportive than discriminatory reaction when others knew about their HIV status.

<sup>7</sup> The disclosure here could only be inferred since we do not know whether the health worker had to know after conducting an HIV test for the respondents or not.

that women are closer to their children than men are because of their caring role and hence are more likely to disclose to children than to their partner.

**Table 21: Disclosure of HIV-positive status by sex**

Percentage distribution of respondents who disclosed their HIV-positive status by sex, Rwanda 2008.

Category and by whom	Male	Female	Number	Total
<b>Husband/wife/partner* (N= 1289)</b>				
Told them myself	87.9	77.3	1032	80.1
Someone else told them with my consent	3.1	3.1	40	3.1
Someone else told them without my consent	1.9	1.8	23	1.8
They don't know my HIV status	0.8	1.3	17	1.3
Not applicable	6.9	13.7	177	13.7
<b>Other family member (N= 1236)</b>				
Told them myself	80.7	82.1	1010	81.7
Someone else told them with my consent	2.7	3.3	39	3.2
Someone else told them without my consent	3.6	4.3	51	4.1
They don't know my HIV status	5.7	5.2	66	5.3
Not applicable	7.3	5.1	70	5.7
<b>Children in household (N= 1244)</b>				
Told them myself	77.4	83.9	1023	82.2
Someone else told them with my consent	2.8	1.5	23	1.8
Someone else told them without my consent	3.8	4.2	51	4.1
They don't know my HIV status	7.9	4.6	68	5.5
Not applicable	8.2	5.7	79	6.4
<b>Friends/neighbours (N= 1193)</b>				
Told them myself	78.1	78.0	931	78.0
Someone else told them with my consent	2.6	3.1	35	2.9
Someone else told them without my consent	8.1	8.9	104	8.7
They don't know my HIV status	6.5	5.5	69	5.8
Not applicable	4.8	4.4	54	4.5
<b>Other people living with HIV (N= 1296)</b>				
Told them myself	93.9	94.8	1225	94.5
Someone else told them with my consent	1.7	1.1	14	1.1
Someone else told them without my consent	0.9	0.8	11	0.8
They don't know my HIV status	1.2	0.9	12	0.9
Not applicable	2.3	2.6	34	2.6
<b>Co-workers (N= 1049)</b>				
Told them myself	51.4	46.1	499	47.6
Someone else told them with my consent	2.4	2.5	26	2.5
Someone else told them without my consent	2.8	4.2	40	3.8
They don't know my HIV status	5.2	5.3	55	5.2
Not applicable	38.3	41.9	429	40.9
<b>Religious leaders (N= 1071)</b>				
Told them myself	66.9	67.4	720	67.2
Someone else told them with my consent	2.0	1.8	20	1.9



Someone else told them without my consent	2.7	2.8	30	2.8
They don't know my HIV status	7.8	10.4	104	9.7
Not applicable	20.5	17.6	197	18.4
<b>Community leaders (N= 1048)</b>				
Told them myself	70.5	68.6	724	69.1
Someone else told them with my consent	2.5	2.6	27	2.6
Someone else told them without my consent	2.9	4.4	42	4.0
They don't know my HIV status	8.3	8.8	91	8.7
Not applicable	15.8	15.6	164	15.6
<b>Healthcare workers (N= 1133)</b>				
Told them myself	92.1	92.8	1049	92.6
Someone else told them with my consent	1.6	1.4	17	1.5
Someone else told them without my consent	1.3	0.7	10	0.9
They don't know my HIV status	0.7	0.6	7	0.6
Not applicable	4.3	4.5	50	4.4
<b>Social workers/counsellors (N= 1206)</b>				
Told them myself	89.3	91.8	1099	91.1
Someone else told them with my consent	2.2	1.5	20	1.7
Someone else told them without my consent	0.6	0.6	7	0.6
They don't know my HIV status	1.6	1.5	18	1.5
Not applicable	6.3	4.7	62	5.1
<b>Government officials (N = 1075)</b>				
Told them myself	63.7	56.6	630	58.6
Someone else told them with my consent	2.0	2.0	21	2.0
Someone else told them without my consent	3.3	3.3	39	3.6
They don't know my HIV status	8.2	8.2	107	10.0
Not applicable	22.9	22.9	278	25.9
<b>Employer/boss (N = 901)</b>				
Told them myself	22.9	21.3	214	23.8
Someone else told them with my consent	1.9	2.0	18	2.0
Someone else told them without my consent	1.5	3.0	23	2.6
They don't know my HIV status	4.2	4.4	39	4.3
Not applicable	62.5	69.3	607	67.4
<b>Clients (N = 893)</b>				
Told them myself	23.0	17.8	172	19.3
Someone else told them with my consent	1.2	1.4	12	1.3
Someone else told them without my consent	1.6	3.0	23	2.6
They don't know my HIV status	6.7	8.3	70	7.8
Not applicable	67.5	69.6	616	69.0
<b>Injecting drug partners (N = 858)</b>				
Told them myself	10.4	7.9	74	8.6
Someone else told them with my consent	1.3	1.3	11	1.3
Someone else told them without my consent	0.0	0.8	5	0.6
They don't know my HIV status	2.1	1.8	16	1.9
Not applicable	86.3	88.2	752	87.6
<b>Teachers* (N = 878)</b>				

Told them myself	32.2	30.8	275	31.2
Someone else told them with my consent	1.6	0.6	8	0.9
Someone else told them without my consent	1.6	2.4	19	2.2
They don't know my HIV status	5.7	4.7	44	5.0
Not applicable	57.6	61.5	532	60.4
<b>The media (N = 895)</b>				
Told them myself	20.9	17.5	165	18.4
Someone else told them with my consent	0.8	0.6	6	0.7
Someone else told them without my consent	1.2	0.8	8	0.9
They don't know my HIV status	8.0	9.4	81	9.0
Not applicable	69.1	71.6	635	70.9

Respondents were asked about how often they felt pressure to disclose their HIV status. Table 22 shows the percentage of distribution of respondents who reported they had felt pressure from people to disclose their HIV status.

Majority of the respondents (62.1 percent) reported that they often “felt” pressure to disclose their HIV status from other individuals not living with HIV (e.g. family members, social workers, and NGO employees).

**Table 22: Pressure from people to disclose HIV status**

Percentage distribution respondents who reported they had felt pressure from people to disclose their HIV status by sex, Rwanda 2008.

Source of pressure	Male	Female	Number	Total
<b>From other PLHIV or from groups/network of PLHIV (N = 1359)</b>				
Often	17.9	18.8	252	18.5
A few times	4.1	3.4	49	3.6
Once	12.1	12.8	171	12.6
Never	65.9	65.0	887	65.3
<b>From other individuals not PLHIV (e.g. family members, social workers, NGO employees) (N = 1455)</b>				
Often	65.1	61.0	903	62.1
A few times	3.1	3.5	49	3.4
Once	6.5	7.0	100	6.9
Never	25.3	28.6	403	27.7

Table 23 shows the percentage of distribution of respondents who reported what they had felt concerning their HIV status confidentially by sex.

Approximately seventy-four percent of the respondents reported they felt confident medical records are kept confidential.

**Table 23: Feeling re confidentiality of HIV status results**

Percentage distribution of respondents who reported they had felt their HIV status had not being confidentially adhered to by sex, Rwanda 2008.

Confidentiality aspects	Male	Female	Number	Total
<b>A health care professional told other people about the</b>				

<b>HIV status without consent (N = 1090)</b>				
Yes	7.6	7.0	109	35.2
No	63.6	65.2	981	64.8
<b>Confidentiality of the medical records related to HIV status (N = 1322)</b>				
Sure medical recodes are kept completely confidential	71.2	74.7	975	73.8
Not sure that medical recodes are kept confidential	26.3	22.4	311	23.5
Sure medical recodes are not kept confidential	2.4	2.8	36	2.7

Respondents were asked about the reactions of these people when they first knew about their HIV status. Table 24 shows the percentage distribution of perceived reactions categories ranging from very discriminatory to very supportive. Husband/wife/partner and children in the family showed a statistically significant difference by sex.

In general, the respondents reported a more supportive than discriminatory reaction. With majority of the respondents reporting that the reaction of social workers and health care workers to be very supportive. Again children in the family and other PLHIV were supportive when they knew about the respondents HIV status. Not applicable responses were also large.

**Table 24: Reaction of the first knowledge about HIV status:**

Percentage distribution of reactions from different people when they found out respondent was HIV positive by sex, Rwanda 2008.

<b>Category of people</b>	<b>Male</b>	<b>Female</b>	<b>Number</b>	<b>Total</b>
<b>Husband/wife/partner* (N = 1227)</b>				
Very discriminatory	11.3	15.2	174	14.2
Discriminatory	4.9	6.4	74	6.0
No difference	15.3	12.3	161	13.1
Supportive	30.1	21.5	292	23.8
Very supportive	26.1	19.5	261	21.3
Not applicable	12.3	25.0	265	21.6
<b>Other adult family members (N = 1214)</b>				
Very discriminatory	13.2	14.7	174	14.3
Discriminatory	4.1	7.9	84	6.9
No difference	14.8	14.3	175	14.4
Supportive	36.8	31.5	399	32.9
Very supportive	16.4	18.4	217	17.9
Not applicable	14.8	13.2	165	13.6
<b>Children in the family * (N = 1179)</b>				
Very discriminatory	12.2	12.5	146	12.4
Discriminatory	3.6	8.1	82	7.0
No difference	15.6	14.1	171	14.5
Supportive	31.9	36.2	414	35.1
Very supportive	18.6	18.1	215	18.2
Not applicable	18.2	10.9	151	12.8

<b>Friends/neighbours (N = 1155)</b>				
Very discriminatory	12.0	14.3	158	13.7
Discriminatory	12.3	13.3	151	13.1
No difference	18.8	21.1	237	20.5
Supportive	26.3	25.4	296	25.6
Very supportive	12.3	12.4	143	12.4
Not applicable	18.2	13.5	170	14.7
<b>Other PLHIV (N = 1208)</b>				
Very discriminatory	9.2	8.3	103	8.5
Discriminatory	0.9	1.8	19	1.6
No difference	18.8	16.2	204	16.9
Supportive	40.3	45.0	528	43.7
Very supportive	23.7	25.0	298	24.7
Not applicable	7.1	3.7	56	4.6
<b>Co-worker (N = 1068)</b>				
Very discriminatory	7.7	7.7	82	7.7
Discriminatory	6.4	4.0	50	4.7
No difference	11.0	10.1	111	10.4
Supportive	16.1	16.8	177	16.6
Very supportive	8.7	9.8	101	9.5
Not applicable	50.2	51.6	547	51.2
<b>Employers/boss (N = 939)</b>				
Very discriminatory	5.7	6.0	56	6.0
Discriminatory	3.4	2.9	29	3.1
No difference	5.0	4.4	43	4.6
Supportive	8.8	7.5	74	7.9
Very supportive	6.5	7.2	66	7.0
Not applicable	70.5	71.8	671	71.5
<b>Clients (N = 942)</b>				
Very discriminatory	5.5	6.0	55	5.8
Discriminatory	2.0	2.5	22	2.3
No difference	5.9	5.7	54	5.7
Supportive	6.3	4.2	45	4.8
Very supportive	4.3	7.0	59	6.3
Not applicable	75.9	74.7	707	75.1
<b>Injecting drug users (N = 901)</b>				
Very discriminatory	3.7	3.7	33	3.7
Discriminatory	0.4	1.4	10	1.1
No difference	2.9	2.4	23	2.6
Supportive	3.3	3.5	31	3.4
Very supportive	2.9	2.7	25	2.8
Not applicable	86.9	86.3	779	86.5
<b>Religious leaders (N = 1090)</b>				
Very discriminatory	4.8	6.0	62	5.7
Discriminatory	2.0	1.6	19	1.7
No difference	15.0	19.1	196	18.0

Supportive	33.4	32.0	353	32.4
Very supportive	14.7	15.7	168	15.4
Not applicable	30.0	25.6	292	26.8
<b>Community leader (N = 1054)</b>				
Very discriminatory	8.4	9.4	96	9.1
Discriminatory	2.8	4.7	44	4.2
No difference	19.2	19.3	203	19.3
Supportive	31.1	33.3	345	32.7
Very supportive	13.3	12.5	134	12.7
Not applicable	25.2	20.8	232	22.0
<b>Health care workers (N = 1122)</b>				
Very discriminatory	5.0	6.9	72	6.4
Discriminatory	1.0	0.5	7	0.6
No difference	7.3	7.9	87	7.8
Supportive	43.3	45.3	502	44.7
Very supportive	34.7	34.5	388	34.6
Not applicable	8.7	4.9	66	5.9
<b>Social workers/counsellors (N = 1150)</b>				
Very discriminatory	6.4	7.8	85	7.4
Discriminatory	1.6	0.8	12	1.0
No difference	8.7	8.6	99	8.6
Supportive	43.9	47.7	537	46.7
Very supportive	30.8	28.2	332	28.9
Not applicable	8.7	6.9	85	7.4
<b>Teachers (N = 906)</b>				
Very discriminatory	5.6	4.6	44	4.9
Discriminatory	2.8	1.5	17	1.9
No difference	5.6	5.2	48	5.3
Supportive	9.6	14.2	117	12.9
Very supportive	8.8	8.7	79	8.7
Not applicable	67.7	65.8	601	66.3
<b>Government official (N = 1063)</b>				
Very discriminatory	7.5	5.5	64	6.0
Discriminatory	2.0	2.1	22	2.1
No difference	17.6	16.0	175	16.5
Supportive	21.7	22.9	240	22.6
Very supportive	10.8	10.3	111	10.4
Not applicable	40.3	43.2	451	42.4
<b>The media (N = 941)</b>				
Very discriminatory	3.8	3.8	36	3.8
Discriminatory	1.1	1.2	11	1.2
No difference	4.2	2.9	31	3.3
Supportive	7.6	7.4	70	7.4
Very supportive	5.3	5.8	53	5.6
Not applicable	77.9	78.9	740	78.6

## SECTION 3C: Treatment

This section sought to investigate the current health status, the health seeking behaviour, and treatment of AIDS and opportunistic infections of the respondents. The information collected helps to determine the potential demand and unmet need for AIDS treatment. For example, the question on self-reported health status has been observed to be closely related to demand for health services, burden of disease and mortality (Idler and Benyamini, 1997). Across countries, the self-reported health status has been observed to be associated with economic status and quality of health care of countries. A study in the Democratic Republic of Congo with women caregivers of HIV/AIDS affected spouses showed poor health (Kipp et al, 2006); while a high 88 per cent of adults in Canada reported their health to be 'good' or 'very good'.

Table 25 shows the percentage distribution of respondents who reported receiving one form of treatment to improve their HIV-positive status by sex. Respondents who had a discussion with a health care professional on other subjects such as sexual reproductive health in the last 12 months showed a statistically significant difference by sex.

About 69 percent of the respondents described their health as fair and poor, combined. Almost 80 percent of respondents were currently taking ARV treatment; a slightly lower percentage (73 percent) reported having access to ARV treatment even though they were not currently taking them. A higher percentage (84 percent) reported that they are currently taking medication to prevent or treat opportunistic infections. However, only 69 percent reported that they had access to medication for opportunistic infections, even though they were not currently taking it. Majority of the respondents (75 percent) had a discussion with a health care professional on the subject of HIV related treatment options in the last 12 months.

### Key Messages: Treatment

- Though 46 percent of the respondents described their health as fair, almost one in every four respondents reported having poor health status.
- Majority of respondents have access to ARV treatment and treatment for opportunistic infections.
- Majority of the respondents (75 percent) had discussions with a health care professional on the subject of HIV related treatment options in the last 12 months.

**Table 25: Treatment to improve HIV-positive status by sex**

Percentage distribution of respondents who reported receiving, having access and discussing treatment to improve their HIV-positive status by sex, Rwanda 2008.

Treatment aspects	Male	Female	Number	Total
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<b>Description of one's health at the moment (N = 1444)</b>				
Excellent	4.1	2.8	45	3.1
Very good	5.1	5.7	80	5.5
Good	21.0	23.3	328	22.7
Fair	47.7	44.8	658	45.6
Poor	22.1	23.4	333	23.1
<b>Currently taking ARV treatment (N = 1498)</b>				
Yes	81.2	78.7	1189	79.4
No	18.8	21.3	309	20.6
<b>Have access to ARV treatment even if not currently taking it (N = 1505)</b>				
Yes	74.0	72.2	1094	72.7
No	21.9	24.5	358	23.8
Don't know	4.1	3.3	53	3.5
<b>Currently taking medication to prevent or treat opportunistic infection (N = 1503)</b>				
Yes	84.8	83.6	1261	83.9
No	15.2	16.4	242	16.1
<b>Have access to medication of opportunistic infection even if is not currently taken (N = 1495)</b>				
Yes	66.9	69.3	1026	68.6
No	33.1	30.7	469	31.4
<b>Had discussion with a health care professional on the subject of HIV related treatment option in the last 12 months* (N = 1501)</b>				
Yes	81.8	72.3	1124	74.9
No	18.2	27.7	377	25.1
<b>Had discussion with a health care professional on other subject such as sexual reproductive health in the last 12 months (N = 24)</b>				
Yes	93.8	95.8	23	95.8
No	6.2	4.2	1	4.2

### SECTION 3D: Experience of having children

This section relates to the respondent's experience of having children. There is new evidence to show that ART restores fertility (e.g. Hornsy et al, 2009). Antiretroviral therapy (ART) may influence the biological, social and behavioural determinants of pregnancy in HIV-infected women. In a prospective cohort study design following 733 HIV-infected women on ART over a 24 month period in Uganda, increased sexual activity and pregnancy incidence were observed (Homsy et al, 2009). This study emphasises the need to provide family planning services along with ART as a standard of care. However, the information that health providers give to HIV-infected women may be ill-informed and violate their reproductive rights.

Table 27 shows the percentage of distribution of respondents who received counselling on other sexual reproductive options after having been diagnosed with HIV.

There was a statistically significant difference by sex for respondents who were advised not to have a child, coerced by a health care professional into being sterilised because of their HIV-positive status, and ARV treatment conditional on the use of certain forms of contraception.

Majority (88 percent) of the respondents reported that they have children. Sadly, almost three quarters of them had children who are known to be HIV-positive.

#### **Key Messages: Experience of having children**

- Majority (88 percent) of the respondents reported that they have children. Sadly, almost three quarters of them had children who are HIV-positive.
- Seventy-seven percent of the respondents reported being advised not to have children. It is worrying that 23 percent have been coerced by a health care worker into being sterilised because of their HIV-positive status.
- A small percentage of women had been coerced by health care professionals to terminate pregnancy (five percent), method of giving birth (12 percent) and infant feeding practices (19 percent).
- Over half of the female respondents reported that they had received ARV for PMTCT.
- However, it is a concern that about 13 percent of the respondents reported that they did not know such treatment existed; and 20 per cent of respondents reported that they were not given information about healthy pregnancy and

**Table 27: Experience of having children by sex**

Percentage distribution of respondent's experience of having children by sex, Rwanda 2008.

Reproduction experience	Male	Female	Number	Total
<b>Have children (N=1517)</b>				
Yes	90.5	87.4	1339	88.3
No	9.5	12.6	178	11.7
<b>If yes are any of your children known to be HIV positive (N=1287)</b>				
Yes	73.4	72.7	938	72.9
No	26.6	27.3	349	27.1
<b>Received counselling re reproductive options after been diagnosed of HIV* (N = 1465)</b>				
Yes	89.8	91.1	1329	90.7
No	9.0	8.8	129	8.8
Not applicable	1.3	0.2	7	0.5
<b>Ever been advised not to have a child since diagnosed with HIV* (N = 1483)</b>				
Yes	65.0	81.0	1141	76.9
No	12.3	13.2	192	12.9
Not applicable	22.7	5.9	150	10.1
<b>Have been coerced by a health care professional into being sterilized because of HIV-positive status* (N = 1486)</b>				
Yes	19.3	24.0	338	22.7



No	66.7	68.6	1012	68.1
Not applicable	14.0	7.4	136	9.2
<b>ARV treatment conditional on the use of certain forms of contraception* (N = 1452)</b>				
Yes	17.2	12.6	200	13.8
No	66.1	77.7	1085	74.7
Not applicable	11.4	6.1	108	7.4
Don't know	5.3	3.6	59	4.1

Table 28 shows that female respondents were asked about their reproductive choices and prevention of mother to child transmission.

A small percentage of women reported being coerced by health care professionals to terminate pregnancy (five percent), method of giving birth (12 percent) and infant feeding practices (19 percent).

Furthermore, Table 28 shows the percentage of distribution of female respondents who have been given ARV to prevent mother to child transmission of HIV during pregnancy.

Over half of the respondents reported they had received ARV for PMTCT. However, it is a concern that about 13 percent of the respondents reported that they did not know such treatment existed.

About 20 percent of the respondents reported that they were not given information about healthy pregnancy and motherhood as part of the programme to prevent mother-to-child transmission of HIV.

**Table 28: Reproductive choices for females**

Percentage distribution of female respondents' reproductive choices given them, Rwanda 2008.

<b>Coerced by health care professional</b>	<b>Percent</b>	<b>Number</b>
<b>Termination of pregnancy (abortion)* (N=803)</b>		
Yes	4.5	36
No	80.5	648
Not applicable	16.2	119
<b>Method of giving birth* (N = 762)</b>		
Yes	12.0	88
No	71.9	529
Not applicable	16.2	145
<b>Infant feeding practices * (N = 754)</b>		
Yes	19.2	145
No	60.2	454
Not applicable	20.6	155
<b>Have been given ARV to prevent mother to child transmission of HIV during pregnancy* (N = 836)</b>		
Have received such treatment	54.8	458
Don't know that such treatment existed	13.2	110
Refusal of such treatment	2.3	19
Did not have access to such treatment	5.9	49

Was not HIV positive when pregnant	23.9	200
<b>Were given information about healthy pregnancy and motherhood as part of the programme to prevent mother-to child transmission of HIV (N = 671)</b>		
Yes	79.9	536
No	20.1	135

## Discussion and Action points:

Ministry of Health/GNIS/IRRP when the woman is already pregnant, a sign that unprotected sex has taken place. The data for both males and females suggest that the woman's pregnancy triggered both partners to test. This needs further investigation to understand partner-communication and male involvement in PMTCT programmes. Testing before entering into sexual relationships should also be encouraged.

2. There is a need to develop evidence-informed counselling protocols to help couples with at least one HIV-infected partner to make family planning decisions.
3. There is an opportunity to develop the capacity of networks of PLHIV to influence decision in policies and programmes. The survey results show only 28 per cent of respondents knew of a Rwandan law which protects the rights of PLHIV.
4. The survey results suggest the coverage of PMTCT from this study can be improved as some respondents were not aware of. There is a need to create more awareness on PMTCT.
6. Over two-thirds of study participants self-reported their health status as either 'fair' or 'poor'. This is typical of developing countries. Self-reported health status is known to be a reasonable indicator of burden of disease and demand for health care services. About half of respondents lived on less than \$1 a day and reported spending at least a day without food. The Government of Rwanda needs to prepare enforcement mechanisms of maintaining quality of life the general population while specifically ensuring that for the HIV positive are not worse off
5. Given that most individuals only test when the woman is already pregnant, a sign that unprotected sex has taken place, testing before entering into sexual relationships should be encouraged.

### Researchers (including IPPF developers of Stigma Guide):

1. It is recommended that in future surveys with PLHIV the following data regarding reproductive behaviour be collected:
  - a. Marriage order (i.e. 1<sup>st</sup>, or 2<sup>nd</sup> marriage) of respondents.

- b. For those who were previously married, reasons for resolution marriage and/or cause of widowhood.
- c. Fertility desire of respondents before and after starting to live with HIV.

This information will help better understand family planning decisions and rights of PLHIV, and sexual relationships in the context of HIV risk for couples.

2. There is a need to research more on qualitative aspects of reproductive choices such as family planning, pregnancy termination, and method of giving birth, and feeding practices such as infant feeding practices, from the perspective of mothers and health and social care workers.
3. The role of various service delivery organisations in addressing stigma and discrimination in Rwanda needs to be examined further. The study findings show that the majority of respondents reported that the reaction of social workers and health care workers was very supportive. This suggests that stigma and discrimination needs to be understood from the perspectives of different service providers including faith based and community based organisations.

## Appendix 1: List of research team members

### RRP+ Fieldworkers

1. Philomene Cyurinyana
2. Innocent Rubagumya, Sociologue
3. Viviane Furaha, pharmacienne
4. Tuyisabe Adrolata Humaniste en sciences de l'education /08596202
5. Dushimimana Marcelline Humaniste sciences Infirmiere 03159628
6. Ntawuyangira Seraphine /Humanite pedagogique/03231254
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9. Ndahamungu Emmanuel
10. Abraham Lincoln 08457137
11. Nsengiyunva Balthazar
12. Ingabire Gloriose 03160406
13. Habineza Claude
14. Uwabasinga Rose 08530468
15. Nizeyimana Isabelle 08595245
16. Majambere Anatole
17. Bigilimana Célestin 08536255
18. Emile de l'assoc IRATUZI: 08472573
19. Mwunvaneza Sebastien
20. Nkurikiyinfura Juvénal

### AVVAIS:

Madam Chantal NYIRAMANYANA (In-charge of survey)

### RRP+:

Joseph Gumuyire

### Data processing and analysis

Alice NYIRAMANYANA

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### Research Project Managers (Consultants):

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Chiweni Chimbwete, International Consultant, ([cchimbwete@masazidevelopment.co.za](mailto:cchimbwete@masazidevelopment.co.za))

## **Appendix 2: List of sampled districts**

1. Kamonyi and Nuhanga
2. Gisagara
3. Bugesera
4. Gasabo
5. Nyarugenge
6. Rwamagana
7. Rulindo
8. Musanze
9. Yangugu
10. Ngororero

## Appendix 3: Stigma Index survey Questionnaire (in Kinyarwanda)

### IBIBAZO BYEREKEYE AKATO N'IHEZWA KU BABANA N'AGAKOKO GATERA SIDA

#### IGIKA CYA 1 :

#### UMWIRONDORO W'UBAZWA

1. IGITSINA
  1. Gabo
  2. Gore
  
2. Ufite imyaka ingahe y'ubukure ?  
-Wavutse ryari ?  
-Ufite imyaka ingahe ?
  
3. Hashize igihe kingana iki ubana n'agakoko gatera SIDA ?  
Imyaka :
  
4. Ni mubuhe buryo ubana n'umukunzi wawe ?
  1. Ndubatse / mbana n'inshuti yanjye munzu
  2. Ndubatse / mbana n'inshuti yanjye ariko ikorera rimwe na rimwe hanze
  3. Ni inshuti ariko ntituba hamwe
  4. Ndi ingaragu
  5. Twaratandukanye
  6. Ndi umupfakazi
  
5. Umaze igihe kingana gite ubana n'inshuti/umugabo/umugore ?  
Imyaka .....
  
6. Waba ukora imibonano mpuzabitsina muri iki gihe?
  1. Yego
  2. Oya
  
7. Waba uri cyangwa warigeze kuba mu cyiciro kimwe mubi kurikira ?
  1. Umugabo ugira imibonano mpuzabitsina n'abandi bagabo
  2. Umugore ugira imibonano mpuzabitsina n'abandi bagore
  3. Transgenderiste (Waba ufite imyitwarire itandukanye n'iyi igitsina yawe)
  4. Indaya kumpamvu y'amafaranga
  5. Gukoresha ibiyobyabwenge hakoreshejwe inshinge
  6. Impunzi cyangwa uwasabye ubuhungiro

7. Kuvanwa mubyawe
8. Uwasigajwi inyuma n'amateka
9. Umwimukira kumpamvu z'imirimo
10. Imfungwa
11. Ntabwo ndi kandi sinigeze mboneka mu cyiciro na kimwe mubivuzwe haruguru

8. Waba ufite ubumuga runaka ku umubiri (Hatarimo indwara y'igikatu nka SIDA)

1. Yego
2. Oya

Niba ari yego, sobanura mumagambo avunaguye ubwo bumuga

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9. Ni ayahe mashuri wize ? Umukarani yandika imyaka yize

1. Ntabwo nize amashuri asanzwe(formelle)
2. Amashuri abanza
3. Amashuri y'isumbuye
4. Amashuri makuru/Kaminuza

10. Uri muruhe rwego rw'akazi mu byiciro bikurikira ? Hitamo icyiciro kimwe cyangwa byinshi ukurikije uko ubyisangamo.

1. Ndi umukozi uhoraho
2. Ndi nyakabyizi
3. Nkora buri gihe ariko nikorera imirimo yanjye bwite
4. Nikorera utwanjye rimwe na rimwe
5. Nta akazi mfite

11. Ubana n'abantu bangahe munzu bari mubyiciro by'ubukure bikurikira ?

1. Abana hagati y'imyaka 0-14
2. Abasore hagati y'imyaka 15-19
3. Abakuze hagati y'imyaka 20-24
4. Abakuze hagati y'imyaka 25-29
5. Abakuze hagati y'imyaka 30-39
6. Abakuze hagati y'imyaka 40-49
7. Abakuze hagati y'imyaka 50+

12. Mufite abana bangahe b'impfubyi za SIDA ?

Andika umubare .....

13. Waba utuye hamwe muhakurikira ?

1. Mucyaro
2. Mumugi muto cyangwa mumudugudu
3. Umugi munini/ ku icyicaro cy'Intara

14. Ni uwuhe mutungo mwunguka buri kwezi, mu mezi 12 ashize ?

1. Andika mumanyarwanda umubumbe w'amafaranga wabonye Mu mezi 12 ashize.....
2. Umukarane w'ibarura yandika uwo mubare  
- Muma faranga y'Urwanda.....

15. Mu kwezi gushize, hari nk'iminsi ingahe uwo mubana mumuryango wawe ataboye ibyo kurya bihagije ?

Andika umubare w'iminsi.....



**IGIKA CYA KABIRI A (2 A) UBUNARARIBONYE BWawe KUBIJYANYE N'IHEZWA N'AKATO BIKORWA N'ABANDI BANTU**

1a. Mu mezi 12 ahise, ni kangahe waba warahejwe mu bikorwa cyangwa mu birori rusange (urugero : ubukwe, gushyingura, ibirori, za clubs) hitamo kimwe mu bikurikira :

1. Nta na rimwe
2. Rimwe gusa
3. Rimwe na rimwe
4. Kenshi

Niba igisubizo ari Nta na rimwe, jya kukibazo 2a.

1b. Niba byarakubayeho byaba byaratewe n'iki ?

1. Kubera ko mbana n'agakoko gatera SIDA
2. Kuzindi mpamvu zinyuranye
3. Kubera ubwandu mfite n'inzindi mpamvu
4. Sinzi impamvu

2a. Mu mezi 12 ahise, wahejwe kangahe mubikorwa by'iyoboka Mana cyangwa by'amashengesho?

- 1 Nta na rimwe
- 2 Rimwe gusa
- 3 Rimwe na rimwe
- 4 Kenshi

Niba igisubizo ari Nta na rimwe, jya kukibazo 3a.

2b. Niba byarakubayeho, byaba byaratewe n'iki ?

1. Kubera ko mbana n'agakoko gatera SIDA
2. Kuzindi mpamvu zinyuranye
3. Kubera ubwandu mfite n'inzindi mpamvu
4. Sinzi impamvu

3a. Mu mezi 12 ahise, waba warahejwe mubijyanye n'imirimo yo murugo ? ( urugero, guteka ibyo kurya, gusangira ibyo kurya, kurara mucyumba kimwe). Hitimo kimwe mubikurikira :

- 1 Ntana rimwe
- 2 Rimwe gusa
- 3 Rimwe narimwe
- 4 Kenshi

Niba igisubizo ari Nta na rimwe jya kukibazo 4a.

3b. Niba byarakubayeho, byaba byaratewe n'iki ?

1. Kubera ko mbana n'agakoko gatera SIDA
2. Kuzindi mpamvu zinyuranye
3. Kubera ubwandu mfite n'inzindi mpamvu
4. Sinzi impamvu

4a. Mu mezi 12 ahise, nikangahe wamenye ibijyanye nuko bagufata ko uri uvuga menshi cyangwa usa nusakuza?

1. Nta narimwe
2. Rimwe gusa
3. Rimwe na rimwe
4. Kenshi

Niba igisubizo ari nta narimwe, jya kukibazo 5a.

4b. Niba byarakubayeho... ( hitamo kimwe mubikurikira) :

1. Kubera ko mbana n'agakoko gatera SIDA
2. Kuzindi mpamvu zinyuranye
3. Kubera ubwandu mfite n'inzindi mpamvu
4. Sinzi impamvu

5a. Mu mezi 12 ahise, ni kangahe wahuye n'ibitutsi, gutotezwa n'ibindi bibi byagukorewe ?

1. Nta narimwe
2. Rimwe gusa
3. Rimwe na rimwe
4. Kenshi

Niba igisubizo ari Nta na rimwe, jya kukibazo 6a.

5b. Niba byarakubayeho, hitamo kimwe mubi kurikira :

1. Kubera ko mbana n'agakoko gatera SIDA
2. Kuzindi mpamvu zinyuranye
3. Kubera ubwandu mfite n'izindi mpamvu
4. Sinzi impamvu

6a. Mu mezi 12 ahise, ni kangahe watotejwe ku mubiri? Hitamo kimwe mubikurikira:

1. Nta narimwe
2. Rimwe gusa
3. Rimwe na rimwe
4. Kenshi

Niba igisubizo ari Nta na rimwe, jya kukibazo 7a.

6b. Niba byarakubayeho, hitamo kimwe mubikurikira :

1. Kubera ko mbana n'agakoko gatera SIDA
2. Kuzindi mpamvu zinyuranye
3. Kubera ubwandu mfite n'inzindi mpamvu
4. Sinzi impamvu

7a. Mu mezi 12 ahise, ni kangahe wigeze ukubitwa

1. Nta narimwe
2. Rimwe gusa
3. Rimwe na rimwe
4. Kenshi

7c. Niba warigeze gukubitwa, ninde wagukubise ?

1. Umugabo wanjye/ umugore wanjye/ inshuti yanjye
2. Undi muntu tubana murugo
3. Undi muntu cyangwa abandi bantu tutabana murugo ariko tuziranye
4. Umuntu ntazi

8. Niba mubibazo kuva 1 – 7, wasubije ko wigeze kugirirwa akato cyangwa ihezwa ku impamvu yuko ubana n'agakoko gatera sida, hitamo imwe mumpamvu zikurikira yabiteye :

1. Kugira imibonano mpuzabitsina n'uwo muhuje igitsina.
2. Uburaya
3. Gufata ibiyobya bwenge hakoreshejwe inshinge
4. Ubuhunzi cyangwa kwaka ubuhungiro
5. Kuvanwa mu byacu
6. Uwashigajwe inyuma n'amateka/kavukire
7. Umukazi wimuka kenshi
8. Imbohe/gereza
9. Nta mpamvu nimwe mbona muzivuzwe haruguru.

Niba ntamapmvu ubonye muri lisiti yatanzwe haruguru, sobanura impamvu ubona wowe ubwawe waragiriwe akato cyangwa ihezwa.

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9. Mu mezi 12 ahise, nikangahe washyizwe kunkenke n'uwo mwashakanye kugirango akumerere nabi ?

1. Nta na rimwe
2. Rimwe gusa
3. Rimwe na rimwe

4. Kenshi

10. Mu mezi 12 ahise, nikangahe wangiwe gukora imibonano mpuzabitsina kumpamvu yuko wanduye aga koko gatera sida ? Hitamo kimwe mubikurikira :

1. Nta na rimwe
2. Rimwe gusa
3. Rimwe na rimwe
4. Kenshi

11. Mu mezi 12 ahise, ni kangahe wahejwe n'abandi bantu babana n'agakoko gatera Sida ? Hitamo kimwe mubikurikira :

1. Nta na rimwe
2. Rimwe gusa
3. Rimwe na rimwe
4. Kenshi

12. Mu mezi 12 ahise, ni kangahe wahejwe n'uwo mwashakanye, inshuti cyangwa abo mubana murugo bitewe nuko ubana n'agakokoko gatera sida? Hitamo kimwe mu bikurikira :

1. Nta na rimwe
2. Rimwe gusa
3. Rimwe na rimwe
4. Kenshi

13. Niba warigeze guhezwa cyangwa warahuye n'ikibazo cy'akato kubera ko ubana n'agakoko gatera sida Mu mezi 12, usanga byaratewe n'iki ? Hitamo ingingo imwe cyangwa nyinshi mu zikurikira :

1. Abantu batinya ko nabanduza virusi itera sida
2. Abantu ntibazi neza uko virusi ya sida yandura, batinya ko nabanduza mbakozeho
3. Abanduye agakoko gatera sida bagira isoni, banga kunyegera ngo batabangereranya nabo.
4. Imyizerere yo mu idini runaka imyumvire yaburi umwe wese
5. Abantu ntibakunda uko mbaho cyangwa ntibakunda uko nitwara
6. Uburwayi bumbonekaho kubera ibimenyetso by'indwara ya sida
7. Simbizi, ntabwo numva neza impamvu

## **IGIKA 2B. IBIJYANYE N'UMURIMO UKORA, UBUZIMA N'AMASHULI**

1a. Mu mezi 12 ahise, ni kangahe wahinduye icumbi cyangwa wananiwe kwishyura inzu ukodesha ? Hitamo kimwe mubikurikira :

1. Nta na rimwe
2. Rimwe gusa
3. Rimwe narimwe
4. Kenshi

1b. Niba byarakubayeho, hitamo kimwe mubikurikira :

1. Kubera ko mbana n'agakoko gatera Sida
2. Kubera impamvu runaka cyangwa impamvu zinyuranye
3. Kubera ko mbana n'agakoko gatera Sida n'izindi mpamvu zinyuranye
4. Ntabwo nzi impamvu

2 a. Mu mezi 12 ahise, ni kangahe watakaje akazi (niba wari umukozi) cyangwa wabuze aho ukura ibyinjira murugo (niba wari uwikorera ku giti cye cyangwa nyakabyizi ?

1. Nta na rimwe
2. Rimwe gusa
3. Rimwe narimwe
4. Kenshi

2b. Niba byarakubayeho, hitamo kimwe mubikurikira :

1. Kubera ko mbana n'agakoko gatera Sida
2. Kubera impamvu runaka cyangwa impamvu zinyuranye
3. Kubera ko mbana n'agakoko gatera Sida n'izindi mpamvu zinyuranye
4. Ntabwo nzi impamvu

2c. Niba byaratewe n'ubwandu bw'agakoko ka Sida ufite, watakaje akazi cyangwa izindi nyungu zinjizaga umutungo murugo ? Hitamo kimwe mu bikurikira :

1. Kumpamvu y'akato nagiriwe n'umukoresha cyangwa abo twakoranaga
2. Nahagaritse akazi kumpamvu z'uburwayi bwananiye
3. Kubera izimpamvu zombi (akato mukazi n'ubuzima bubi)
4. Kubera izindi mpamvu

3. Mu mezi 12 ahise, wavukijwe amahirwe yo kubona akazi bitewe n'ubwandu bw'agakoko gatera Sida ufite ?

1. Yego
2. Oya

4a. Mu mezi 12 ahise, ni kangahe wahinduriwe imirimo cyangwa wangiwe kuzamurwa mu ntera kubera ku babana n'agakoko gatera Sida ?

1. Nta na rimwe
2. Rimwe gusa
3. Rimwe narimwe
4. Kenshi
5. Ntibindeba

4b. Niba ari uko bimeze byatewe na.... (hitamo kimwemu bikurikira)

1. Byatewe n'akato cyangwa guhezwa natewe n'umukoresha cyangwa n'abo twakoranaga
2. Kubera ko ntarinshoboye gukora imirimo imwe n'imwe
3. Kubera guhezwa n'ubuzima bubi.
4. Izindi mpamvu

5. Mu mezi 12 ahise, ni kangahe wirukanwe cyangwa wahagaritswe cyangwa wangiwe kwiga mu ishuli runaka kubera ko ubana n'agakoko gatera Sida?

1. Nta na rimwe
2. Rimwe gusa
3. Rimwe narimwe
4. Kenshi
5. Ntabwo bindeba

6. Mu mezi 12, ni kangahe umwana cyangwa abana bawe birukanwe cyangwa bahagaritswe cyangwa bangiwe kujya mu ishuli runaka bitewe nuko wowe ubwawe ubana n'agakoko gatera Sida ?

1. Nta na rimwe
2. Rimwe gusa
3. Rimwe narimwe
4. Kenshi
5. Ntabwo bindeba

7. Mu mezi 12 ahise, ni kangahe wangiwe kwivuzwa muri rusange harimo yenda n'amenyo kubera ko ubana n'agakoko gatera Sida ? (hitamo kimwe mu bikurikira) :

1. Nta na rimwe
2. Rimwe gusa
3. Rimwe narimwe
4. Kenshi
5. Ntabwo bindeba

8. Mu mezi 12 ahise, waba warigeze kwangirwa ibijyanye no kuringaniza imbyaro kubera ko ubana n'agakoko gatera Sida ? (hitamo kimwe mubikurikira).

1. Nta na rimwe
2. Rimwe gusa
3. Rimwe narimwe
4. Kenshi
5. Ntabwo bindeba

9. Mu mezi 12 ahise, waba warigeze kwangirwa ibijyanye na serivisi y'imyororokere/kuringaniza imbyaro, imibonano mpuzabitsina bitewe nuko ubana n'agakoko gatera Sida ?

1. Yego
2. Oya

## IGIKA 2C. IHEZWA RY'UMUNTU KU GITI CYE N'IMPAGARARA

1. Mu mezi 12 ahise, wigeze kwiyumvamo bimwe mu bikurikira ? Hitamo uko wumva umeze kimwe kuri buri ngingo mu zikurikira :

- |                                     |      |     |
|-------------------------------------|------|-----|
| 1. Isoni :                          | Yego | Oya |
| 2. Numva nicira urubanza :          | Yego | Oya |
| 3. Ndirenganya nituka :             | Yego | Oya |
| 4. Ndenganya abandi :               | Yego | Oya |
| 5. Numva ndi mubi :                 | Yego | Oya |
| 6. Ndumva ngomba igihano :          | Yego | Oya |
| 7. Numva nakwiyahura nkava kw'isi : | Yego | Oya |

2. Mu mezi 12 ahise, waba warahisemo kimwe mu bikurikira kubera ko ubana n'agakoko gatera sida ? (Hitamo kimwe gusa kuri buri ngingo mu zikurikira) :

- |   |      |     |
|---|------|-----|
| 1. Nahisemo kutajya mu mahuriro n'abandi bantu :  | Yego | Oya |
| 2. Nahunze umuryango wanjye n'inshuti :   | Yego | Oya |
| 3. Nahisemo guhagarika akazi :  | Yego | Oya |
| 4. Nahisemo kudasaba akazi cyangwa kuzamurwa mu ntera :   | Yego | Oya |
| 5. Nahisemo guhagarika amasomo cyangwa amahugurwa cyangwa sinashatse uburyo bwo gukomeza amashuri ndetse n'amahugurwa : | Yego | Oya |
| 6. Nahisemo kutubaka/gushaka :  | Yego | Oya |
| 7. Nahisemo kudakora imibonano mpuzabitsina :   | Yego | Oya |
| 8. Nahisemo kutabyara cyangwa kutongera kubyara :   | Yego | Oya |
| 9. Nahisemo kutajya ku Kigo nderabuzima kinyegereye nubwo bwose nari mbikeneye :  | Yego | Oya |
| 10. Nahisemo kutajya ku bitaro kandi narimbikeneye :  | Yego | Oya |

3. Mu mezi 12 ahise, waba waratewe ubwoba nabimwe mu bikurikira ko byakugeraho?

- |   |      |     |
|---|------|-----|
| 1. Kunegurwa :                          | Yego | Oya |
| 2. Gutukwa cyangwa gutotezwa mu mvugo : | Yego | Oya |
| 3. Kunengwa ku mubiri:                  | Yego | Oya |
| 4. Gukubitwa :                          | Yego | Oya |

4. Mu mezi 12 ahise, waba wari ufite impungenge ko umuntu runaka yanga gukorana nawe imibonano mpuzabitsina kubera ko ubana n'agakoko gatera sida ?

1. Yego
2. Oya



## IGIKA 2D. UBURENGANZIRA, AMATEGEKO NA POLITIKI

1a. Wigeze kumva itangazo ry'abiyemeje guharanira kurinda uburenganzira bw'ababana n'agakoko gatera Sida ?

1. Yego
2. Oya

1b. Niba igisubizo ari yego, wigeze gusoma cyangwa kuganira kuri iryo tangazo ?

1. Yego
2. Oya

2a. Waba uzi itegeko/politiki y'igihugu cyawe cyangwa amabwiriza arengera ubana n'agakoko gatera SIDA

1. Yego
2. Oya

2b. Niba igisubizo ari yego, vuga iryo tegeko.

.....

2c Niba ari uko biri wigeze kujya mu biganiriro bivugira kuri iyo politike, itegeko cyangwa amabwiriza ?

1. Yego
2. Oya

3. Mu mezi 12 ahise, waba kimwe mubikurikira cyaba cyara kugezeho ?

1. Nategetswe kwipimisha agakoko gatera sida
2. Nangiwe ubwishingizi bw'indwara cyangwa ubwishingizi bw'ubuzima kuko nanduye agakoko gatera sida
3. Narafunzwe cyangwa narezwe mu inkiko kubera ko mbana n'agakoko gatera sida
4. Byabaye ngombwa ko mvuga ibijyanye n'ubwandu bwanjye bw'agakoko gatera sida kugira ngo mbashe kwinjira mukindi gihugu.
5. Narahagaritswe cyangwa nashyizwe mukato no kwigizwayo
6. Ntana kimwe mubivuzwe haruguru cyangezeho

4a. Mu mezi 12 ahise, bumwe mu uburenganzira nk'umuntu ubana n'agakoko gatera sida ntibwubahirijwe ?

1. Yego
2. Oya

Niba igisubizo ari oya, jya ku gika gikurikira : (igika 2 E : Kuzana impinduka)

4b. Niba igisubizo ari yego, waba warigeze kwiyambaza ubutabera nk'umuntu ubana n'agakoko gatera sida ngo bukurenganure ?

1. Yego
2. Oya
3. Simbizi

Niba igisubizo ari oya cyangwa simbizi, jya ku kibazo 4e.

4c. Niba igisubizo ari yego, mbese wabitangiye mu mezi 12 ahise?

1. Yego
2. Oya

4d. Wabonye ibihe bisubizo ?

1. Ikibazo cyarakemuwe
2. Ikibazo kiracyari munzira yo gukemurwa
3. Ikibazo nticyigeze gikemurwa

4e. Ni igisubizo ku kibazo 4b ari Oya cyangwa ntabizi, kuki ubutabera butiyambajwe ?

1. Ntabushobozi bw'amafaranga yo kubishyira mu bikorwa
2. Nasanze inzira yo gukemuriramo ibibazo by'ubutabera ari ndende kandi hasabwa byinshi
3. Naciwe intege cyangwa se natewe ubwoba bwo kubishyira mu bikorwa
4. Umuntu runaka yangiriye inama yo kubishyira mu bikorwa
5. Nashidikaniye ko haricyo byatanga
6. Nta na kimwe mubivuzwe haruguru

5a. Nk'umuntu ubana n'agakoko gatera sida, wigeze wiyambaza umukozi cyangwa abakozi ngo bagire icyo bakora mugihe uburengazira bwawe butari bwubahirijwe ?

1. Yego
2. Oya

Niba igisubizo ari oya, jya ku kibazo 6a.

5b. Niba igisubizo ari yego, byabaye mu mezi 12 ahise ?

1. Yego
2. Oya

5c. Niba igisubizo ari yego, byatanze ikihe gisubizo ?

1. Ikibazo cyarakemuwe
2. Ikibazo kiri munzira yo gukemurwa
3. Ikibazo nticyigeze gikemurwa

6a. Wigeze kwiambaza umuyobozi wo mu nzego zibanze cyangwa n'uwo mu nzego zo hejuru ngo agufashe mu gihe wavukijwe uburenganzira bwawe nk'umuntu ubona n'agakoko gatera sida ?

1. Yego
2. Oya

Niba igisubizo ari oya, jya ku gika gikurikira (Igika 2E : Kuzana impinduka)

6b. Niba igisubizo ari yego, byabaye mu mezi 12 ahise ?

1. Yego
2. Oya

6c. Niba igisubizo ari yego byatanze ikihe gisubizo ?

1. Ikibazo cyarakemutse
2. Ikibazo kiri munzira yo gukemuka
3. Ikibazo nticyigeze gikemuka

## IGIKA 2E : KUZANA IMPINDUKA

1. Mu mezi 12 ahise, wigeze kuganiriza cyangwa kwigisha umuntu waguha akato cyangwa washakaga kuguheza ?

- 1 Yego
- 2 Oya

2a. Ese waba uzi umuryango cyangwa imiryango wakwiyambaza mu gihe waba uhejwe cyangwa uhawe akato ku mpamvu yuko ubana n'agakoko ka sida ?

1. Yego
2. Oya

Niba igisubizo ari oya, jya ku ikibazo 3.

2b. Niba igisubizo ari yego, ni iyihe miryango uzi? Hitamo ibisubizo byinshi niba ari ngombwa muri ibi bikurikira:

1. Imitwe y'abafasha abanduye agakoko gatera sida
2. Amashyirahamwe y'ababana n'ubwandu bw'agakoko gatera sida
3. Umuryango utegamiye kuri Leta wo mu Karere
4. Abihayimana
5. Ababuranira abandi (Avoka)
6. Umuryango ushinzwe kurengera uburenganzira bwa muntu
7. Umuryango nyarwanda utegamiye kuri Leta wo kurwego rw'igihugu
8. Komisiyo y'igihugu ishinzwe kurwanya Sida
9. Umuryangompuzamahanga utegamiye kuri Leta (ONG)
10. Ibindi :

2c. Niba wahisemo igisubizo « ibindi », sobanura mu magambo avunaguye ibyo uwo muryango :

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-----  
-----  
-----

3. Mu gihe wahuye ni ikibazo cyo guhezwa cyangwa cyo guhabwa akato, wigeze wiyambaza imwe mu miryango yavuzwe haruguru ngo igufashe ?

1. Yego
2. Oya

4. Niba warigeze gukemura ikibazo cyo guhabwa akato cyangwa no guhezwa wowe ubwawe cyangwa ufashijwe n'abandi bantu, vuga muri make uko ikibazo cyarigitewe, ninde wagufashije kandi wagenjeje ute cyangwa uwagufashije yabigenje ate ?

Vuga uko ikibazo cy'iheweza cyangwa icy'akato cyari giteye :

-----  
-----  
-----  
Niba hari abandi bantu bagufashije gukemura ikibazo, ninde wagufashije ?

-----  
-----  
-----  
Wabyifashemo ute cyangwa abandi bagufashije bate gukemura icyo kibazo?

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-----  
5a. Mu mezi 12 ahise, wafashije muburyo bunyuranye abandi bantu babana n'agakoko gatera sida ?

1. Yego
2. Oya

5b. Niba igisubizo ari yego, ni iyihe nkunga wateye? (Hitamo ikirenze kimwe niba ari ngombwa)

1. Naramuganirije, mugira inama/inkunga y'ibitekerezo nshingiyeye kubyo nanyuzemo
2. Natanze inkunga y'amafaranga cyangwa ibyo kurya, nabafashije kugera aho batashoboraga kwigerera
3. Nabarangiyeye aho serivisi zitandukanye zitangirwa

6. Waba uri umunyamuryango w'urugaga rufasha abantu babana n'agakoko gatera sida?

1. Yego
2. Oya

7. Mu mezi 12 ahise, wigeze gufasha nk'umuntu udaharanira inyungu cyangwa umukozi muri porogaramu cyangwa umushinga (uwa Leta cyangwa uwigenga) ufasha ababana n'agakoko gatera sida?

1. Yego
2. Oya

8. Mu mezi 12 ahise, waba waragiye mu Manama agamije gushyiraho ingamba/amategeko /amabwiriza cyangwa politike kubijyanye no kurwanya agakoko gatera sida?

1. Yego
2. Oya

9. Wiyumvamo ubushobozi bwo kuba wazana impinduka mubijyanye no gufata ibyemezo kuri bimwe mu bikurikira? (Hitamo byinshi niba ari ngombwa)

1. Ibibazo by'amategeko/ubucamanza bibangamira ababana n'agakoko gatera sida
2. Politike y'Ubuyobozi bw'inzege z'ibanze ibangamira ababana n'agakoko gatera sida
3. Imishinga yo mu karere igamije gushyigikira ababana n'agakoko gatera sida
4. Politike y'igihugu igamije kurengera ababana n'agakoko gatera sida
5. Porogaramu cyangwa imishinga kurwego rw'igihugu igamije guteza imbere ababana n'agakoko gatera sida
6. Ibyemezo mpuzamahanga
7. Nta na kimwe mu bivuzwe haruguru

10. Hari imiryango myinshi y'ababana n'agakoko gatera sida irwanya ihezwa no gukumirwa bikorerwa ababana n'agakoko gatera sida. Mbese umwe muri iyi miryango ikubajije ikibazo kigira kiti: "ni ikihe kintu cy'ingirakamaro twakora nk'umuryango ngo turwanye ikumirwa n'ihazwa"? Wasubiza iki? (Hitamo ingingo imwe gusa mu zikurikira):

1. Gukora ubuvugizi kubijyanye n'uburenganzira bw'abantu bose babana n'agakoko gatera sida
2. Gufasha ababana n'agakoko gatera sida binyujijwe mu nama, amafaranga, no kurangirwa/kwoherezwa aho babona ubufasha
3. Ubuvugizi kubijyanye n'uburenganzira bw'abahezwa cyane (urugero rw'abagira imibonano mpuzabitsina kw'abahuje ibitsina, abafata ibiyobya bwenge binyuze mu inshinge, abakora umwuga w'uburaya) no kubafasha
4. Kwigisha ababana n'agakoko gatera sida uburyo bwiza bwo kubana nako gakoko (cyane cyane kumenya neza ibijyanye no gufata imiti).
5. Gukangurira no kumenyekanisha indwara ya sida muri rubanda

### IGIKA 3 A. ISUZUMWA

1. Ni impamvu ki yaguteye kwisuzumisha agakoko gatera sida? (Hitamo imwe cyangwa nyinshi mu ingingo zikurikira):

1. Akazi/umurimo
2. Inda (gutwita)
3. Niteguraga kurushinga cyangwa kugira imibonano mpuza bitsina
4. Nabisabwe n'ikigo nderabuzima kimaze kubona ko narindwaye indwara zandurira mumibonano mpuzabitsina
5. Nabisabwe n'ikigo nderabuzima bahereye ku ibimenyetso nagaragazaga by'indwara ya sida harimo n'igituntu
6. Umugabo/umugore/umwe mu umuryango yasanze yaranduye
7. Uburwayi cyangwa urupfu rw'umugabo/ umugore/ inshuti/ umwe mu muryango
8. Nashakaga gusa kubimenya/ amatsiko
9. Ibindi

Niba wahisemo igisubizo ibindi, watanga impamvu:-----  
-----  
-----  
-----  
-----

2. icyemezo cyo kwipimisha wagifashe wowe wenyine?

- Yego nafashe icyemezo cyo kwipimisha nyenyine, ni ukuvuga ko hari k'ubushake bwanjye.
- Nafashe icyemezo cyo kwipimisha mbishishikarijwe n'abandi
- Nafashe icyemezo cyo kwipimisha mbahaswe, ntabishaka
- Napimwe ntabizi, nabimenye gusa ari uko bamaze kumpima

3. Wahawe inama mu gihe wipimishaga agakoko gatera sida? (Hitamo ingingo imwe gusa):

1. Yego nahawe inama mbere na nyuma yo gupimwa
2. Nahawe inama mbere yo gupimwa gusa
3. Nahawe inama nyuma yo gupimwa gusa
4. Nta nama n'imwe nahawe mu gihe nipimishaga

### IGIKA 3 B. IBIJYANYE NO GUTANGA IBISUBIZO CYANGWA KUBIGIRA IBANGA

1. Vuga uko abantu cyangwa ihuriro ry'abantu bakurikira, bamenye iby'uko ubana n'agakoko gatera sida ubwa mbere.  
(Hitamo akarenze kamwe mu tuzu dutambika mu gihe igisubizo gitandukanye ku bantu bavugwa)

Icyemezo	Narabimubwiye	Undi muntu yaramubwiriye mbimuhereye uruhusa	Undi muntu yaramubwiye ntaruhusa namuhaye	Ntabwo bazi ibijyanye n'ubwandu bwanjye	Ntabwo bindeba
Abantu / inzego					
Umugabo/umugore/ Inshuti					
Abakuze bo mu muryango					
Abana tuvukana					
Inshuti/ abaturanyi					
Abandi babana n'agakoko gatera sida					
Abo mukorana					
Umukoresha					
Abakiliya					
Abo musangira urumogi munshinge					
Abayobozi b'itorero/ Idini					
Abakuru b'imiryango					
Abavuzi					
Abajyanama/ abatanga ubufasha					
Abarimu					
Abayobozi b'inzego za Leta					
Ibinyamakuru					

2a. Ni kangahe washishikarijwe n'ababana n'agakoko gatera sida cyangwa ababa mu rugaga rw'ababana n'agakoko gatera sida ngo ubabwire ibijyanye n'uko ubana n'agakoko gatera sida?

1. Kenshi
2. Rimwe na rimwe
3. Rimwe gusa
4. Nta na rimwe

2b. Ni kangahe wahatiwe n'abandi bantu batabana n'agakoko gatera sida ( urugero, abo mu muryango wawe, abajyanama/ abasosiyali, abokorera imiryango itegamiye kuri Leta) kugira ngo bamenye ibijyanye n'uko ubana n'agakoko gatera sida?

1. Kenshi
2. Rimwe na rimwe



3. Rimwe gusa
4. Nta na rimwe

3. Umuvuzi w'umuganga (umuforomo cyangwa ukora muri laboratwari) yaba yarabwiye abandi bantu ibijyanye n'uko ubana n'agakoko gatera sida utabimuhereye uburenganzira?

1. Yego
2. Oya
3. Simbizi

4. Wumva dosiye yawe yo kwa muganga ibitswe mu ibanga?

1. Sinshidikanya ko dosiye yanjye ibitswe kwa muganga mu ibanga rikomeye
2. Ntabwo nzi neza niba dosiye yanjye ibitswe neza kwa muganga mu ibanga
3. Byangaragariye ko dosiye yanjye itabitswe neza kwa muganga mu ibanga

5. Wabonye abantu bifashe bate muri rusange mu gihe bamenyeshejwe ubwa mbere ibijyanye n'uko ubana n'agakoko gatera sida? ( Hitamo akazu kamwe kuri buri cyiciro cy'abantu).  
(Ushyiremo akamenyetso kuri nti bindeba mu gihe uzi neza ko abo bantu batazi ibijyanye n'uko ubana n'agakoko gatera sida cyangwa igihe utamenye uko bitwaye bacyumva iyo nkuru).

	Guhezw	Guhezwa	Nta	Kunyitaho	Kunyitaho	Ntibindeba
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icyemezo	a cyane		tandukaniro		cyane	
Abantu / inzego						
Umugabo/umugore/ Inshuti						
Abakuze bo mu muryango						
Abana tuvukana						
Inshuti/ abaturanyi						
Abandi babana n'agakoko gatera sida						
Abo mukorana						
Umukoresha						
Abakiliya						
Abo musangira urumogi mu nshinge						
Abayobozi b'itorero/ Idini						
Abakuru b'imiryango						
Abavuzi						
Abajyanama/ abatanga ubufasha						
Abarimu						
Abayobozi b'inzego za Leta						
Abanyamakuru/ itangazamakuru						

6. Mbese wasanze kuvuga ibijyanye n'uko ubana n'agakoko gatera sida hari icyo byakumariye? ( Hitamo ntibindeba niba utari wabwira abantu ibijyanye n'uko ubana n'agakoko gatera sida).

1. Yego
2. Oya
3. Ntibindeba

### **IGIKA 3 C. IBIJYANYE N'UBUVUZI**

1. Watubwira muri rusange uko ubuzima bwawe bumeze muri iki gihe?

1. Burahebuje
2. Ni bwiza cyane
3. Ni bwiza
4. Ni ibisanzwe
5. Ni bubi

2. Mbese uri ku miti muri iki gihe?

1. Yego
2. Oya

2b. Ushobora kubona imiti igabanya ubukana bw'agakoko gatera sida nubwo utaba uri ku miti muri iki gihe? Kubona imiti bisobanura ko imiti ihari kandi ku buntu cyangwa wayigurira.

1. Yego
2. Oya
3. Simbizi

3a. Ufata imiti muri iki gihe murwego rwo kwikingira cyangwa kuvura indwara z'ibyuririzi?

1. Yego
2. Oya

3b. Ushobora kubona imiti y'ibyuririzi nubwo waba utayifata muri iki gihe? Kubona imiti y'ibyuririzi bisobanura ko iboneka kandi ku buntu cyangwa ufite ubushobozi bwo kuyigurira.

1. Yego
2. Oya

4. Mu mezi 12 ahise, waba waragize ibiganiro byubaka hamwe n'abavuzi ku byerekeye imibonano mpuzabitsina, ubuzima bw'imyororokere, ubuzima bwiza bwo mu mutwe, kunywa ibiyobyabwenge n'ibindi?

1. Yego
2. Oya

### IGIKA 3 D. IBIJYANYE NO KUGIRA ABANA

Ibibazo kuva 1-5 bireba ibitsina byombi, abagabo n'abagore

1a. Ufite umwana/abana ?

1. Yego
2. Oya

1b. Niba igisubizo ari yego, umwe cyangwa benshi yaba yaranduye agakoko gatera sida?

1. Oya
2. Yego

2. Kuva aho wamenyeye ko ubana n' agakoko gatera sida, wahawe inama ku bijyanye n'ubuzima bw'imyorokere?

1. Yego
2. Oya

3. Mbese hari umuvuzi wakugiriye inama yo kudatwita kuva aho wamenyeye ko ubana n' agakoko gatera sida?

1. Yego
2. Oya
3. Ntibindeba

4. Mbese hari umuvuzi wigeze aguhatira kwifungisha ibyara mu gihe wamenye ko ubana n'agakoko gatera sida?

1. Yego
2. Oya
3. Ntibindeba

5. Mbese kubona imiti igabanya ubukana biterwa nuko ukoresha bumwe mu buryo bwo kuringaniza imbyaro?

1. Yego
2. Oya
3. Ntibindeba
4. Simbizi

Ibibazo 6 na 7 bireba abagore gusa

6. Mu mezi 12 ahise, waba warahaswe n'umwe mu bavuzi kubijyanye n'ingingo zikurikira?

1. Gukuramo inda	Yego	Oya	Ntibindeba
2. Uburyo bwo kubyara	Yego	Oya	Ntibindeba
3. Uburyo bwo kugaburira Uruhinja	Yego	Oya	Ntibindeba

7 a. Wigeze gufata imiti itanga amahirwe yo kugabanya ubwandu bw'agakoko gatera sida buva kuri nyina bujya ku mwana? (Hitamo ingingo imwe muri izi ngingo zikurikira):

1. Yego, nafashe imiti
2. Oya, sinamenye ko iyo miti ibaho
3. Oya, banyangiye gufata iyo miti
4. Oya, sinashoboye kubona iyo miti
5. Oya, ntabwo nabanaga n'agakoko gatera sida igihe nari ntwite.

7b. Niba igisubizo ari yego, wahawe impanuro/inama ku bijyanye no gutwita ndetse no kubyara neza bikubiye muri porogaramu yo kwirinda kwanduza agakoko gatera sida umwana ?

1. Yego
2. Oya

IGIKA 3 E. INGORANE/ IBIBAZO BINYURANYE

Ni izihe ngorane zikomeye uhuranazo mu bi kurikira :

1. Kwipimisha agakoko gatera sida :

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2. Kuvuga cyangwa se kubika ibanga ku bwandu bw'agakoko gatera sida :

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3. Imiti igabanya ubukana bw'agakoko gatera sida

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4. Kugira umwana cyangwa abana kandi umuntu abana n'agakoko gatera sida :

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## **Appendix 4 Ethical Clearance Letter from CNLS:**

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