A study funded by PRIVACY INTERNATIONAL

RESEARCH FINDINGS

PRIVACY & CONFIDENTIALITY FOR PLHIV ACCESSING HEALTH SERVICES
Table of Contents

List Of Tables 4
List Of Figures 5
Glossary 6
Acknowledgement 7
Executive Summary 9

1.0 CHAPTER ONE: INTRODUCTION AND BACKGROUND 10
1.1 Research Objectives 11
1.1.1 Specific objectives 12
1.2 Methodology 12
1.2.1 Research site 12
1.2.2 Research design 12
1.2.3 Data collection methods 12
1.2.3.1 Quantitative methods 12
1.2.3.2 Qualitative methods 12
1.2.3.3 Secondary sources 12
1.4 Sampling size and procedure 12
1.5 Ethical Issues 12

2.0 CHAPTER TWO: THE LEGAL AND REGULATORY FRAMEWORK GOVERNING PRIVACY AND CONFIDENTIALITY OF PERSONS LIVING WITH HIV IN KENYA 13
2.1 Understanding the right to Privacy and Confidentiality 14
2.2 Why Privacy and Confidentiality are important to the national HIV response 14
2.3 The Constitution of Kenya 2010 15
2.4 The HIV and AIDS Prevention and Control Act (HAPCA), 2006 15
2.5 The National Code of Practice on HIV and AIDS in the Workplace (2009) 17
2.6 The Health Information System Policy (2010-2030) 17
2.7 The National Code of Practice on HIV and AIDS in the Workplace (2009) 17
2.8 The Health Information System Policy (2010-2030) 19
2.9 National Guidelines for HIV testing and counseling in Kenya (2010) 20
2.10 National Patients’ Rights Charter (2013) 21
2.11 Redress for violations with regard to Privacy and Confidentiality 21

3.0 CHAPTER THREE: DEMOGRAPHICS OF THE RESPONDENTS 18
3.1 Respondents’ Distribution 19
3.1.1 Health care workers’ gender and age 19
3.1.2 People living with HIV 19
3.2 Respondents marital status 20
3.3 Respondents’ religious affiliations 20
3.4 State of Ability/disability 20
3.5 Respondents’ residence 20
3.6 Level of education 20
3.7 Employment status and type 21
3.8 Designation at work 22
3.9 Respondent’s monthly income 23
3.10 Interaction with the PLHIV at work 24

4.0 CHAPTER FOUR: LEVEL OF UNDERSTANDING OF HUMAN RIGHTS AND RIGHTS TO PRIVACY IN RELATION HIV AND AIDS 25
4.1 Human rights 26
4.2 Privacy 27
4.3 Main sources of information on human rights and right to privacy 28

5.0 CHAPTER FIVE: AWARENESS ON HIV RELATED LEGAL AND POLICY PROVISIONS RELATING ON THE RIGHT TO PRIVACY AND CONFIDENTIALITY 31
5.1 Level of awareness of the provisions of Chapter four of the constitution 32
5.2 Level of awareness of the provisions HIV and AIDS Prevention and Control Act [HAPCA] 2006 32
5.3 Level of awareness of the provisions of the National guidelines for testing and counseling 33
5.4 Level of awareness of the provisions of the HIV and AIDS tribunal 34
5.5 Level of awareness of Government policy on HIV and AIDS (Kenya National AIDS Strategic Plan 2009/10 to 2012/13) 34
5.6 Knowledge of policy in HIV training curriculum at the Medical Training Centre or medical schools/universities. 34
5.7 Informants’ level of awareness of the provision of policy documents and institutions. 35
5.8 Source of information on HIV and AIDS policy documents and institutions 35

6.0 CHAPTER SIX: BREACH OF THE RIGHT TO PRIVACY AND CONFIDENTIALITY IN RELATION TO HIV 37
6.1 Human rights violation 38
6.2 Breach of rights to privacy within the Health care facility 39
6.3 Circumstances for disclosure of PLHIV’s status without consent 40
6.4 Breach of rights to privacy and confidentiality as institutional requirements 41
6.5 Breach of rights to privacy of PLHIV out of the health care facility. 42

7.0 CHAPTER SEVEN: BREACH OF RIGHTS TO PRIVACY AND STIGMA 44
7.1 Perception/understanding of the term stigma 45
7.2 Main contributor to stigma 46
7.3 Stigma and violence as a result of disclosure 46
7.4 Socio-economic factors privacy and Health seeking behaviour 47
7.5 Policy developments 47

8.0 CHAPTER EIGHT: DISCUSSION 48
8.1 Level of understanding of human rights and rights to privacy in relation to HIV 49
8.2 Level of awareness on HIV related legal and 50
8.3 Breach of the right to privacy and confidentiality in 51
8.4 Breach of rights to privacy and HIV and AIDS related stigma 52

9.0 CHAPTER NINE: SUMMARY, CONCLUSION AND RECOMMENDATIONS 53
9.1 Recommendations 54
9.1.1 Community Education 54
9.1.2 Organize periodic consultative forum between PLHIV and HCWs 55
9.1.3 Training of HCW 55
9.1.4 Education of potential employers through the media 55
9.1.5 Targeted Information and Communication 55
9.1.6 Policy Work 55
9.1.7 Access to Justice 56

APPENDIX 61

Research Questionnaire 62
Focus Group Discussion Guide And Tool 70
List Of Tables

Table 3.1.1 HCW's gender and age
Table 3.1.2 PLHIV’s age and gender
Table 3.6.2 PLHIV respondents gender versus education
Table 3.9.1 Respondents’ monthly income
Table 4.1.1 PLHIV understanding of human rights.
Table 4.1.2 HCW’s understanding of human rights
Table 4.2.1 PLHIV’s understanding of privacy
Table 4.2.2 HCW’s understanding of privacy
Table 4.3.1 Respondent’s main sources of information on human rights and right to privacy
Table 5.2.1 Level of awareness of the provisions HIV and AIDS Prevention and Control Act 2006
Table 5.3.1 Level of awareness of the provisions of National guidelines for testing and counselling
Table 5.7.1 Informants’ level of awareness of the provision of policy documents and institutions.
Table 5.8.1 PLHIV’s Sources of information on HIV and AIDS policy documents and institutions
Table 5.8.2 HCW’s Sources of information on HIV and AIDS policy documents and institutions
Table 6.1.2 HCW’s understanding of human rights violation.
Table 6.3.1 Circumstances for disclosure of PLHIV’s status without consent
Table 7.1.1 Understanding of the term ‘stigma’
Table 7.3.1 Stigma and violence in a gender perspective

List Of Figures

Figure 3.2.1 HCW’s Marital status
Figure 3.2.2 PLHIV’s marital status
Figure 3.2.3 Cumulative number of respondents’ marital status
Figure 3.6.1 PLHIV’s level of education
Figure 3.6.2 HCW’s Level of education
Figure 3.7.1 PLHIV’s employment status
Figure 3.7.2 PLHIV’s type of employment
Figure 3.8.1 PLHIV designation at work place
Figure 3.8.2 HCW designation at work place.
Figure 3.9.1 PLHIV’s and HCW’s monthly income
Figure 3.10.1 HCW’s level of interaction with PLHIV at work
Figure 3.10.2 PLHIV’s level of interaction with other PLHIVs at work
Figure 4.3.3 Main sources of information on human right and rights to privacy
Figure 5.1.1 Respondents’ level of the provisions
Figure 5.2.1 Level of awareness of the provisions of the HIV and AIDS Prevention and Control Act 2006
Figure 5.3.1 Level of awareness of the provisions of National guidelines for testing and counseling
Figure 5.4.1 Level of awareness of the provisions of HIV and AIDS tribunal
Figure 5.5.1 Level of awareness of Government policy on HIV and AIDS
Figure 5.6.1 Knowledge of policy in HIV training curriculum at the Medical Training institutions
Figure 5.7.1 Informants’ level of awareness of the provision of policy documents and institutions
Figure 6.2.1 Reasons for inability of HCW to obtain consent from PLHIV
Figure 6.3.1 Circumstances when HCW is allowed to disclose the HIV status of individuals without their consent.
Figure 6.4.1 Breach of rights to privacy and confidentiality through institutional requirements
Figure 6.5.1 Privacy guidelines on HIV data storage
Figure 6.6.1 Breach of PLHIVs rights without their consent
Figure 6.7.1 Breach of PLHIV’s rights to privacy out of the health care facility.
Figure 6.7.2 Adolescent’s rights to privacy
Figure 7.2.1 main source of stigma
Figure 7.3.1 Stigma or violence as a result of disclosure
I take this opportunity to express my gratitude to the research team and participants who were instrumental in the successful completion of this research. The insights of these participants and the sharing of their experiences provided invaluable information for people working in health care settings to address the right to privacy and confidentiality against people living with HIV.

I would like to appreciate the Principal Investigator Dr. Charles Muga, Co-Investigators; Dr. David Bukusi, Prof. Fred Were, Dr. Keziah Koduol, Mr. Nelson Otwoma, Mr. Ambrose Rachier, Ms. Melba Katindi and Mr. Edgar Makona for their untiring efforts in ensuring that the study meets its intended objectives.

Special appreciation goes to the Research Team for their excellent support. Mr. Shadrack Orinda analysed the study results, while Mr. Patrick Kangethe offered legal and logistical support. Ms. Endi Anino was instrumental in recruiting and mobilizing Study Participants. The Chapter on Legal and Regulatory Framework Governing Privacy and Confidentiality of Persons Living with HIV in Kenya was written by Ms. Melba Katindi with support from Naomi Njuguna. The final report was edited by Dr. Gina Alvarado, Mr. Ambrose Rachier and myself. To all of you I say thank you very much!

I would also like to acknowledge the input, guidance and support received from all the implementing partners namely Kenya Paediatric Association (KPA) and the National Empowerment Network of People living with HIV and AIDS in Kenya NEPHAK who identified the participants for the research. Their contribution was vital for the success of the study. We applaud the volunteers who were part of this study for providing such useful information, which may inform evidence-based changes in policy and practices that touch on the right to privacy and confidentiality in Kenya.

Lastly, I wish to thank Kenyatta National Hospital/ University of Nairobi Ethics and Research Committee (KNH/UoN ERC) for approving this study, providing the necessary research work and allowing the use of its facility. And to Privacy International, thank you for funding the study.

Allan Achesa Maleche
Executive Director, KELIN
Executive summary

This study was carried out by KELIN, seeking to review the need to uphold the right to privacy and confidentiality in the context of access to health services for persons living with HIV. The study sought to: determine the level of understanding of human rights in relation to HIV including the right to privacy and confidentiality amongst Health Care Workers (HCW) and Persons Living with HIV (PLHIV); assess awareness on HIV related legal and policy provisions relating to the right to Privacy and Confidentiality and evaluate the incidences of the breach of the right to privacy and confidentiality in relation to HIV.

A national study conducted by KELIN in 2012 established that there was high level of human rights violations against PLHIV in Kenya. One of the key findings of the study was that medical centres routinely fail to recognize the right to privacy of PLHIV, resulting in a violation of their rights. Through funding from Privacy International (PI), a human rights watchdog organization committed to fighting for the right to privacy across the world, KELIN partnered with the Kenya Paediatric Association (KPA) and the National Empowerment Network of People Living with HIV (NEPHAK) to conduct this research, to provide specific information about legal and policy provisions and practices in relation to this right. This detailed information may inform policies and improve the right to privacy and confidentiality in the context of the status of HIV positive patients.

This Research was conducted at the Kenyatta National Hospital (KNH), the largest national referral, teaching and research hospital in Kenya. The process involved random identification and recruitment of study participants: PLHIV were recruited by NEPHAK while the health care workers were recruited by KPA. The study used both qualitative and quantitative approaches where a team of six research assistants administered twenty questionnaires to PLHIV, and another twenty to HCW. Two focus group discussions (FGDs) were also conducted: one with the PLHIV and another with HCW. The FGDs were aimed at generating in-depth information on awareness on the right to Privacy and Confidentiality and instances of breach of the same. The quantitative data were analysed descriptively while the FGDs were analysed thematically, based on the study objectives.

The key findings are:

• There is general basic understanding of the concepts of human rights and on privacy as a human right. The knowledge varies based on the participants’ profession, role or predisposition to interact with the rights. There is a correlation between the level of understanding, the level of education and the medium of access.

• There is low awareness of legal institutions and instruments dealing with human rights violations and HIV related issues. Respondents lack knowledge on specific provisions of the laws or functions of the instruments.

• Breach of rights to privacy and confidentiality of PLHIV occurs within the workplace, health care setting, in the families and insurance companies. Breaches of rights to privacy and confidentiality predominantly occur in the workplace context. Although incidences of disclosure without consent occurred, majority of PLHIV failed to report cases of breach of rights because they lack the knowledge on their rights, are unaware of the procedure and some don’t find it a priority, especially when sick.

• Although the Constitution and laws in Kenya protect the right to privacy and confidentiality for PLHIV, there is poor practical implementation and minimal measures to uphold and ensure this right is safeguarded in health care service delivery.
1.1 Research Objectives

The overall aim of the Research was to establish the extent to which rights to privacy and confidentiality are upheld in health service delivery for PLHIV.

1.1.1 Specific objectives

1. To determine the level of understanding of human rights in relation to HIV, including the right to privacy and confidentiality amongst HCW and PLHIV

2. To assess awareness on HIV related legal and policy provisions relating to the right to privacy and confidentiality

3. Critically evaluate the incidences of the breach of the right to privacy of PLHIV in relation to stigma and how the PLHIV themselves perceive the causes of stigma.

Chapter 8 discusses the study findings in relation to available literature based on the objectives of the study. This chapter gives reasons behind some of the findings in the study. Chapter nine contains the summary, recommendations and conclusions.
1.2 Methodology

1.2.1 Research site
The study was conducted within Kenyatta National Hospital (KNH). KNH is a national, referral, teaching and research institution in Kenya. The hospital has a bed capacity of 1800, out of which 209 beds are for the Private Wing. It has 58 wards, 24 theatres (16 specialised), 20 outpatient clinics and an Accident and Emergency Department. There are 44 departments with an established Comprehensive Care Centre (CCC) that provides specialized HIV care. It has over 6000 staff members. The Hospital sits on 45.7 hectares of land that also incorporates College of Health Sciences (University of Nairobi), the Kenya Medical Training College, National Laboratory Service (Ministry of Health and Kenya Medical Research Institute (KNH website 2014).

1.2.2 Research design
The study adopted a cross sectional descriptive design involving both quantitative and qualitative methods. Two groups of respondents were interviewed namely health care workers (HCW) and people living with HIV and AIDS (PLHIV) who seek health care services from Kenyatta National Hospital. The study sought to collect information on their knowledge and perceptions on HIV issues relating to matters of privacy and confidentiality.

1.2.3 Data collection methods

1.2.3.1 Quantitative methods
Semi structured interviews
Semi structured interviews were used to source information from 20 health care workers and 20 people living with HIV. This was to reveal their knowledge and perceptions on matters of rights to privacy and confidentiality.

1.2.3.2 Qualitative methods
Focus group discussions
Two focus group discussions (FGDs) were conducted: one with the health care workers (HCW) and another with people living with HIV (PLHIV). The FGDs were meant to verify the information given in the semi-structured interviews and give more insight/reasons and explanations behind the quantitative data. The FGDs were focused on unveiling the general practices and gaps in upholding rights to privacy of HIV positive patients within the health care setting.

1.2.3.3 Secondary sources
The study involved a desk review of the existing literature on laws and policies in relation to the right to privacy and confidentiality in the context of HIV.

1.2.3.4 Data analysis and presentation
The qualitative data collected was transcribed and analysed thematically. Descriptive approach was used where direct, verbatim quotes from the transcripts were used to explain the trends based on the objectives. Quantitative data from the study was analysed descriptively using SPSS. Quantitative and qualitative data was triangulated to build on the objectives of the study.

1.4 Sampling size and procedure
The study used purposive sampling to select twenty HCW for the study. This was meant to sample HCW who have some form of contact with the PLHIV. The HCW were recruited into the study through KPA and NEPHAK. For the PLHIV, convenient sampling was used to sample 20 respondents receiving medical services from KNH with the help of NEPHAK. NEPHAK reached out to the heads of various departments at the facility and informed them of the research and the need for volunteers from the target group. The patients who had come to the clinic on the research date were informed of the study and 20 PLHIV recruited on voluntary basis after discussing the consent form.

1.5 Ethical issues
The study sought for ethical approval from KNH ERC board and informed voluntary participation of respondents. The consent form was discussed with the participants and informed consent given. The participants were informed of the objectives, benefits and risks of participating in the study as well as of the strategies in place to uphold their rights to privacy and confidentiality before participating in the study. The participants appended their signatures to the consent form to show their voluntary consent, Code numbers were used in the questionnaires to uphold privacy and confidentiality.
2.1 Human Rights

Human rights are universal legal guarantees protecting individuals and groups against actions by governments and other third parties which interfere with fundamental freedoms and human dignity. Privacy is a fundamental human right recognized in the Constitution of Kenya 2010 and in several national and international instruments, including the United Nations Declaration of Human Rights (UDHR) and the International Covenant on Civil and Political Rights (ICCPR). In the medical field, confidentiality is an integral part of this right that originates from the Hippocratic Oath.

2.2 Understanding the right to Privacy and Confidentiality

The terms privacy and confidentiality are often used interchangeably. The difference between the two terms brings out the distinct challenges and issues faced by PLHIV in their enjoyment of the right to health.

Privacy refers to the freedom from intrusion into one’s personal matters and information. Confidentiality concerns the manner in which information that an individual has disclosed in a relationship of trust is treated by the person to whom the information has been divulged. It entails an expectation that the information will not be divulged to others in ways that are inconsistent with the understanding of the original disclosure.

Privacy is thus about the person and confidentiality is about data or information that may give away someone’s identity or condition.

2.3 Why Privacy and Confidentiality are important to the national HIV response

Evidence of prevailing levels of stigma and discrimination associated with HIV and related conditions in Kenya validates the need to uphold the right to privacy and confidentiality. People may avoid treatment if they are not confident that information about them will remain private. Patients who seek treatment may also withhold important information out of concern for their privacy, or the fear that confidentiality will be breached. In addition, this concern may prevent patients from receiving full and appropriate treatment. Those tested may be reluctant to take up life-enhancing and life-saving treatments if they fear that someone may see them.

---

## Chapter 2

### Table: Nature of Right, Interpretation, Example of Violations

<table>
<thead>
<tr>
<th>Nature of Right</th>
<th>Interpretation</th>
<th>Example of Violations</th>
</tr>
</thead>
</table>
| Privacy         | Is control over one’s personal matters and circumstances of sharing the same | • Testing a person without their express consent
|                 |                | • Demanding the HIV results of a third party e.g. by employer, pastor, etc. |
| Confidentiality | Concerns the manner in which information that an individual has shared is treated. | • Disclosing someone’s HIV status without their consent.
|                 |                | • Leaving client files where other persons can easily access them. |

---


Section 20 of the Act provides for the formulation of privacy guidelines which would include the use of an identifying code relating to minimal essential information: name, date of birth, sex, identity, social security number, medical information, records or forms used in HIV testing and other related medical assessments. The Cabinet Secretary for the time being is responsible for matters relating to health and is yet to formulate regulations prescribing these privacy guidelines as stipulated in Section 20. In addition, the right to privacy of the person who is requesting for a test or is acting on the instruction of a medical practitioner to a laboratory for an HIV test to be conducted, the forms or the records used in such procedure shall not include any information that directly or indirectly identifies the person to whom the HIV test relates (Section 21). This enhances both privacy and confidentiality of the information generated from the test.

Confidentiality is further enhanced by the provision within the Act on non-disclosure of information concerning the result of an HIV test. Section 12 of the Act provides that the results can be released to the legal guardian or the Registrar of births and deaths where the person on whom the test was conducted, or that person’s partner, personal representative, administrator or executor (if the person has died), or the legal guardian of the child, or the person to whom a power of attorney has been granted if the person is unable to give written consent, or the legal guardian, partner, parent or adult offspring of a person who is incapable of giving consent as a result of disability. Disclosure can also be made to a person who is directly involved in the treatment or the counselling of the person on whom the test has been conducted or for the purposes of an epidemiological study or research or to a competent court where the information is directly relevant to the proceedings or to the Registrar of births and deaths where the person on whom the test has been conducted dies. (Section 22) Disclosure and/or release permitted merely for the purpose of gaining access to any credit or loan services, or for medical, accident or life insurance, or the extension or continuation of such services is not allowed, nor is release by the health or other organization responsible, in the case of life or healthcare services insurance cover, devise a reasonable limit of cover for which the proposer will not be required to disclose his HIV status (section 31(1) and (2).

2.6. Case Law

2.6.1 J. A. O. vs. Home Park Caterers & Metropolitan Hospital HCC No. 38 of 2003 Nairobi

The services of J.A.O, a Kenyan working as a waitress, were terminated by her employer, Home Park Catering Ltd, because they found out she was HIV positive. This information was provided to the employer by a company doctor who had not only failed to seek informed consent to test from JAO, but also failed to seek her consent to share the information about her HIV status.

The petitioner filed a case alleging violation of her constitutional right to privacy. She demanded compensation from the catering firm, the doctor and the hospital. By court of way consent filed in court by parties to the case, made the following declarations:

- that the testing of an employee or prospective employee for HIV without his or her consent constitutes an invasion of her right to privacy;
- that disclosure of an employee’s HIV status to the employer without his or her consent is unlawful;
- that termination of an employee on the basis of his/her HIV status only is unlawful.

The petitioner agreed to pay the petitioner the sum of Kshs. 2,250,000 (About $26000) without admission of liability. This was a landmark case as it was prosecuted at a time when the country did not have specific legal provisions on HIV.

2.7 The National Code of Practice on HIV and AIDS in the Workplace (2009)

The Code of Practice was formulated deriving from the ILO Code of Practice on protection of workers’ personal data. Under the policy, it is illegal to subject any current or prospective staff to HIV testing to inform employment decisions. HIV related information about employees is to be considered confidential and co-workers are not obliged to reveal such information about each other.

2.8 The Health Information System Policy (2010-2030)

This policy seeks to establish a framework for the routine collection of health service data and the conveyance of that data to higher levels of the healthcare system. One of the guiding principles of the policy is the recognition of the right to privacy of individuals and the protection of this right in relation to health information. It also recognizes the need to promote data security and information disclosure in an ethical manner. (Para 2.2)
2.9 National Guidelines for HIV testing and counseling in Kenya (2010) 

These are guidelines formulated by the then Ministry of Public Health and Sanitation under the National AIDS and STD Control Programme (NASCOP). Privacy is ensured by the promotion of private rooms in counselling centres, and in the outreach HIV Testing and Counselling (HTC) centres (which refers to services provided outside of fixed sites e.g. mobile centres or in the workplace). The policy also provides for Home based HIV testing and counselling which seeks to promote more privacy, especially for those who do not wish to be seen going to the VCT centres.

One of the core principles of the policy is that of confidentiality. In maintaining confidentiality, privacy also must be maintained. All the HTC sites must ensure that the policies and infrastructure are such that the confidentiality of the information shared by the patient as well as the manner in which the information is shared is private. Anonymity is no longer necessary as long as confidentiality is upheld and identity only disclosed for purposes of referrals for appropriate care services.

2.10 National Patients’ Rights Charter (2013) 

The National Patients’ Rights Charter, launched in 2013, was informed by the need for patients in Kenya to be aware of their rights and responsibilities. The charter states that a patient has the right to have medical information and treatment records treated as confidential and extends the duty of confidentiality even after a patient’s death.

2.11 Redress for violations with regard to Privacy and Confidentiality

**Courts:**

The Constitution of Kenya 2010 not only allows cases of human rights violations to be heard by the High Court but also the magistrate’s courts, including the Industrial Court in certain circumstances, and provides that there should be no filing fees for such cases, as well as minimal procedural requirements.

**Constitutional Commissions:**

Violations that may particularly affect women, children and persons with disability can be referred to the Kenya National Commission on Human Rights and The National Gender & Equality Commission (Article 59), which promotes both human rights, and the gender and equality mandate.

**Equity Tribunal:**

The 2006 HIV Prevention and Control Act also established the Equity Tribunal in Kenya, which was set up to hear complaints related to any breach of the rights provided for in the Act. The intention of the Tribunal is to speed up the judicial process for HIV related complaints which can take years to resolve through the mainstream court process in Kenya. The Tribunal is designed to be accessible by PLHIV, and the panel was chosen for their expertise in matters related to HIV, human rights, and includes at least one member who is openly living with HIV. The tribunal is able to hear cases resulting in breach of provisions of the HAPCA, including those touching on the right to privacy and confidentiality.

**Statutory Regulatory bodies:**

Patients can lodge complaints with the relevant regulatory authorities such as Medical Practitioners and dentists board, the Nursing council of Kenya, Clinical officers council among others provided in law.
Demographics Of The Respondents

Chapter 3

3.1 Respondents’ Distribution

3.1.1 Health care workers’ gender and age

Of the 20 health care workers interviewed, 35% were male and 65% female as shown in Table 3.1.1 below. The majority (45%) of the HCW respondents were aged 41 years and above. Those between 36 and 40 years old were 26%. Those aged between 26 and 30 years were only 5 percent of the sample, while 10% were between 18 and 25 years of age (Table 3.1.1).

Table 3.1.1 HCW’s gender and age

<table>
<thead>
<tr>
<th>Age</th>
<th>Male %</th>
<th>Female %</th>
<th>Total %</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-25 yrs</td>
<td>5</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>26-30 yrs</td>
<td>0</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>31-35 yrs</td>
<td>0</td>
<td>20</td>
<td>20</td>
</tr>
<tr>
<td>36-40 yrs</td>
<td>10</td>
<td>25</td>
<td>35</td>
</tr>
<tr>
<td>41 yrs or more</td>
<td>20</td>
<td>45</td>
<td>100</td>
</tr>
</tbody>
</table>

3.1.2 People living with HIV

40% of the PLHIV were male and 60% female. (Table 3.1.2) shows the age brackets of the male and female respondents.

Table 3.1.2 PLHIV’s age and gender

<table>
<thead>
<tr>
<th>Age</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-25 years</td>
<td>0</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>26-30 years</td>
<td>5</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>31-35 years</td>
<td>5</td>
<td>15</td>
<td>20</td>
</tr>
<tr>
<td>36-40 years</td>
<td>5</td>
<td>15</td>
<td>20</td>
</tr>
<tr>
<td>41 years or more</td>
<td>25</td>
<td>25</td>
<td>50</td>
</tr>
<tr>
<td>Total % of respondents</td>
<td>40</td>
<td>60</td>
<td>100</td>
</tr>
</tbody>
</table>
3.2 Respondents marital status

Among the HCWs, 20%, 65% and 15% were single, married and widowed respectively. None was divorced. 35% of the PLHIV were single; 45% were married, 5% were divorced and 15% were widows. Overall, the married respondents were cumulatively the highest at 55% followed by singles at 27%

Cumulatively, [both HCWs and PLHIV], 11 respondents were single, 22 married 1 divorced and 6 widowed as shown in figure 3.2.3 below.

3.3 Respondents’ religious affiliations

All the HCWs were Christians while among the PLHIV there was only one Muslim accounting for only 5%.

3.4 State of Ability/disability

None of the PLHIV interviewed had any disabilities while 15% of HCW were living with some kind of disability. Two HCWs were sight impaired and one had physical mobility impairment. Those living with disability were 7.5% of all interviewed respondents. This means that the possibility of disability limiting access to awareness about rights to privacy and confidentiality would only affect less than 10% (ten percent).

3.5 Respondents’ residence

The respondents reside in Nairobi and two other neighbouring counties of Kiambu and Kajiado. The areas of residence depicted middle class and informal settlements for both HCWs and PLHIV.

3.6 Level of education

The HCWs had higher levels of education than the PLHIV. The females also had higher level of education than their male counterparts. This is presented in the table 3.6.1 below where there were 5% post graduate male versus 15% post graduate female. The same applies to the diploma level where the male certificate/diploma holders are half the number of female of the same level of education.

The PLHIV generally had a lower level of education as compared to the health care workers. Despite using convenient sampling and recruiting participants on voluntary basis, there were no graduates among the PLHIV (both bachelor’s degree and post graduate were not registered in this category) as shown in the table 3.6.2 below.

Table 3.6.1 HCW respondents’ gender versus level of education

<table>
<thead>
<tr>
<th>Level of education</th>
<th>HCW Gender versus level of education</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
</tr>
<tr>
<td>Secondary School</td>
<td>10</td>
</tr>
<tr>
<td>Certificate/Diploma</td>
<td>0</td>
</tr>
<tr>
<td>Bachelor’s degree</td>
<td>0</td>
</tr>
<tr>
<td>Post Graduate Degree</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>40</td>
</tr>
</tbody>
</table>

Table 3.6.2 PLHIV respondents gender versus education

<table>
<thead>
<tr>
<th>Level of education</th>
<th>PLHIV Gender versus level of education</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
</tr>
<tr>
<td>Secondary School</td>
<td>10</td>
</tr>
<tr>
<td>Certificate/Diploma</td>
<td>20</td>
</tr>
<tr>
<td>Bachelor’s degree</td>
<td>5</td>
</tr>
<tr>
<td>Post Graduate Degree</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>60</td>
</tr>
</tbody>
</table>
3.7 Employment status and type

The HCWs were 85% employed with 15% volunteers and all reported to be skilled in their areas of work. The PLHIV on the other hand registered 30% unemployment. Out of the employed PLHIV, 37% were employed to do skilled labour, 20% semi-skilled and the other 40% was skilled labour as shown in the figure 2.5.8 below.

Figure 3.7.1 PLHIV’s employment status

![PLHIV’s employment status](image1)

Figure 3.7.2 PLHIV’s type of employment

![PLHIV type of employment](image2)

3.8 Designation at work

For the PLHIV, 45% had no designation at their work place, 10% were human resource persons and the other 45% had informal designations such as driver (5%), security guard (5%), mama chai (tea girl) (5%), onion vendor (5%), marketer, business man, mansions/pastor among others as shown in the diagram below.

Figure 3.8.1 PLHIV designation at work place

![Designation at work](image3)

3.9 Respondent’s monthly income

The general trend of respondents’ income is as shown in the table 3.9.1 below.

Table 3.9.1 Respondents’ monthly income

<table>
<thead>
<tr>
<th>Income Category</th>
<th>HCW</th>
<th>PLHIV</th>
<th>Combined Total</th>
<th>Cumulative total %</th>
</tr>
</thead>
<tbody>
<tr>
<td>No income</td>
<td>0</td>
<td>0</td>
<td>6</td>
<td>15</td>
</tr>
<tr>
<td>Up to Ksh 6,000</td>
<td>3</td>
<td>15</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>From Ksh 6,001 to 15,000</td>
<td>2</td>
<td>10</td>
<td>6</td>
<td>30</td>
</tr>
<tr>
<td>From Ksh 15,001 to 25,000</td>
<td>0</td>
<td>0</td>
<td>5</td>
<td>25</td>
</tr>
<tr>
<td>Above Ksh 25,000</td>
<td>15</td>
<td>75</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>Total</td>
<td>20</td>
<td>100</td>
<td>20</td>
<td>100</td>
</tr>
</tbody>
</table>

As shown in the table above, a majority of PLHIV are low income earners with more than half earning Ksh. 15,000 and below. This contrasts with HCWs where the more than half earn a monthly income of above Ksh. 25,000. While 30% of the PLHIV earned no income at all in a month, no health care worker including the volunteers reported having no income.

![PLHIV’s and HCW’s monthly income](image4)

Figure 3.9.1 PLHIV’s and HCW’s monthly income

Cumulatively, most respondents (75%) earned a monthly salary of Ksh. 25,000 and above. However, only 12% of the respondents in this category were PLHIV. Most PLHIV interviewed were low income earners. This is also reflected by the fact that 100% of those without any monthly income were the PLHIV. Concerning privacy and confidentiality, the level of income of the PLHIV may affect their health seeking behaviour and by extension the acquisition of information about rights to privacy and confidentiality. This may as well lower their ability to attain the rights to privacy and confidentiality.
50% of the PLHIV interviewed reported casual/communicative interaction with other PLHIV at work. 10% reported never having interacted with other PLHIV at work while 15% did not know whether they interact with other PLHIV at work since they did not know their status. The other 25% were unemployed and found the question not applicable to their situation. For the health care workers, there were two levels of interaction: a) contact/physical including interaction with the body fluids of the PLHIV and b) non-physical; e.g. communication through counselling. Most of the health care workers (65%) had physical contact with PLHIV while 35% reported having casual/communicative contact.
Human rights

The understanding of the term human rights was given from both PLHIV and HCW. Human rights were understood and defined in different ways by the PLHIV respondents. The responses were as shown in the table below.

Table 4.1.1 PLHIV understanding of human rights.

<table>
<thead>
<tr>
<th>Chapter 4</th>
<th>Level Of Understanding Of Human Rights And Rights To Privacy In Relation HIV And AIDS</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.1 Human rights</td>
<td>The understanding of the term human rights was given from both PLHIV and HCW. Human rights were understood and defined in different ways by the PLHIV respondents. The responses were as shown in the table below.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>PLHIV</th>
<th>Definition</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Freedom to live and do what you want without interference</td>
<td>25</td>
</tr>
<tr>
<td></td>
<td>Entitlements as a human being</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>Are human rights/ People’s rights that protect from harm</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>Defending, fighting/ advocating for the rights of a person</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Is to have the right to live with HIV and AIDS and to be helped</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Freedom to access basic needs access to health facilities, education, food, shelter etc.</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>I don’t know</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>An organization that protects the rights of people</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Right to be loved and work</td>
<td>5</td>
</tr>
</tbody>
</table>

Majority of the PLHIV respondents (25%) understood the term human rights to mean “freedom to live and do what one would want to do without interference”. This was followed by 20% who understood human rights as entitlements people have by virtue of being human beings. 15% of the PLHIV understood it as what protects people from harm; 10% understood human rights in terms of defending, fighting or advocating for the rights of a person and another 10% defined it as access to basic needs and services such as health, food, water, education etc.

Certain definitions however, showed inadequate/lack of understanding of human rights. For example, 10% of PLHIV defined human rights as the rights to live with HIV and to be helped, while 5% understood it as an organization that fights for human rights. Another 5% felt it is all about the right to be loved. In the PLHIV FGD for example some discussant talked of “doing the right thing”. The most interesting definition from PLHIV was, “it is an organization that protects the rights of people”. In the statements of their understanding, 5% (Five percent) of the PLHIV respondents admitted that they were not aware of the term “human rights”.

From the PLHIV respondents, there seemed to be no link between human rights to privacy, confidentiality while the link to HIV mentioned was “to have a right to live with HIV and to be helped”. This presents inadequate awareness about the link between HIV and human rights.

All HCW claimed to understand the term human rights though they understood and defined it differently as shown in the table below.
The term was defined differently by different respondents. The PLHIV respondents had a general knowledge of what the term privacy means as shown in tables 4.2.1 and 4.2.2 below. A good number of respondents, especially the PLHIV, linked privacy to their status while most health care workers linked it to entitlements as a human being. A majority of the HCW (25 percent) understood privacy in terms of individual/personal matters that one would not want to discuss with others and 15 percent understood privacy in terms of avoiding intrusion into other people's private life or affairs. Though the majority of the respondents emphasized keeping information secret/confidential/private or to one's self, there were some who mentioned or implied the issue of control of information. From the HCW’s FGD more precise statements such as "having control over personal information" were mentioned. From the PLHIV FGD, the discussants implied control over information about their HIV status as shown in the excerpt below.

A few divergent definitions such as "to accept myself the way I am" were also realized. These represented those with inadequate or divergent understanding of the term privacy.

### Table 4.2.1 PLHIV’s understanding of privacy

<table>
<thead>
<tr>
<th>PLHIV’s understanding of privacy</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>An individual’s secret/ Keeping secrets/ Personal information that should not be disclosed to the public</td>
<td>45</td>
</tr>
<tr>
<td>It’s something confidential</td>
<td>15</td>
</tr>
<tr>
<td>Keeping something to yourself and not exposing to others e.g. one’s HIV status</td>
<td>10</td>
</tr>
<tr>
<td>Not disclosing my HIV status/ people’s HIV status</td>
<td>10</td>
</tr>
<tr>
<td>Don’t know</td>
<td>5</td>
</tr>
<tr>
<td>Is to accept myself the way I am</td>
<td>5</td>
</tr>
<tr>
<td>Someone knowing things that I have not disclosed to them</td>
<td>5</td>
</tr>
<tr>
<td>To stay alone and shy from sharing with others</td>
<td>5</td>
</tr>
</tbody>
</table>

### Table 4.2.2 HCW’s understanding of privacy

<table>
<thead>
<tr>
<th>HCW understanding of Privacy</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual/personal matters that you would not want to discuss</td>
<td>25</td>
</tr>
<tr>
<td>Confidentiality/ keeping information confidential</td>
<td>20</td>
</tr>
<tr>
<td>Not intruding into a person’s affairs/ inner life without their consent</td>
<td>15</td>
</tr>
<tr>
<td>Keeping some condition or information to one’s self and being able to decide whom to tell or not to tell</td>
<td>10</td>
</tr>
<tr>
<td>How to conceal information/ limit information from getting to others</td>
<td>10</td>
</tr>
<tr>
<td>Entitlements that can be shared or not shared</td>
<td>5</td>
</tr>
<tr>
<td>Keeping something private</td>
<td>5</td>
</tr>
<tr>
<td>Rights to access all information about one’s self especially in the hospital</td>
<td>5</td>
</tr>
<tr>
<td>Something not to be shared in public without permission</td>
<td>5</td>
</tr>
</tbody>
</table>

Though the respondents presented a closer understanding of privacy there was no clear distinction between privacy and confidentiality. A good number of respondents, especially the PLHIV, linked privacy to their status while most health care workers linked it to the ability to protect someone’s rights to privacy. This shows that the understanding of the term privacy is contextual and depends on the respondents’ setting.

### 4.3 Main sources of information on human rights and right to privacy

Sources of information on privacy that were named including radio, TV, church, mosques, peers and friends among others. The HCW reported to have more sources of information compared to the PLHIV. The additional sources of information that were never accessed/mentioned by the PLHIV include IEC materials and theatre. While HCW got most of their information from partners (10%), the PLHIV accessed more of their information from TV (19%), radio (16%) and peers/friends (9%). The most accessed source of information for both groups was however, TV (13%) followed by Radio (11%) and then Church/Mosques (9%) as shown in table 4.3.1 below.
Figure 4.3.3 Main sources of information on human rights and right to privacy

In the FGDs the sources of information about human rights and rights to privacy mentioned include electronic media such as TV and radio, internet; print media such as magazines and newspapers, brochures and constitution; and other sources such as churches, training, seminars, workshops, partners and friends among others.

When asked about sources of information on rights the FGD some mentioned that they are taught their rights to privacy and confidentiality in church as shown in the excerpt below.

Participant2: Church
Moderator3: Through the church? So how do you know about your rights through the church? Does the church have training, do they tell you or do they preach about the rights?
Participant4: They teach us

The sources of information on human rights are likely to contribute to the trend of the level of understanding of human rights. This is because most of the PLHIV and HCW got their information about human rights and rights to privacy and confidentiality from informal settings such as radio, TV, churches, friends, peers. These are one way sources where the listeners cannot contribute much and does not allow more time for discussions. This calls for an education forum that will allow for two way communication both for the HCW and PLHIV.

Table 4.3.1 Respondent’s main sources of information on human rights and right to privacy

<table>
<thead>
<tr>
<th>Source of information</th>
<th>HCW%</th>
<th>PLHIV%</th>
<th>Combined %</th>
<th>Combined Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td>TV</td>
<td>8</td>
<td>19</td>
<td>13.5</td>
<td>1</td>
</tr>
<tr>
<td>Radio</td>
<td>6</td>
<td>16</td>
<td>11</td>
<td>2</td>
</tr>
<tr>
<td>church/mosque/synagogue</td>
<td>10</td>
<td>8</td>
<td>9</td>
<td>3</td>
</tr>
<tr>
<td>health workers</td>
<td>9</td>
<td>6</td>
<td>7.5</td>
<td>4</td>
</tr>
<tr>
<td>peers/ friends</td>
<td>3</td>
<td>9</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>Newspapers</td>
<td>6</td>
<td>6</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>civil society organization</td>
<td>6</td>
<td>6</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>Partner</td>
<td>10</td>
<td>1</td>
<td>5.5</td>
<td>6</td>
</tr>
<tr>
<td>Magazines</td>
<td>6</td>
<td>4</td>
<td>5</td>
<td>7</td>
</tr>
<tr>
<td>e-newsletter</td>
<td>6</td>
<td>3</td>
<td>4.5</td>
<td>8</td>
</tr>
<tr>
<td>brothers/ sisters</td>
<td>5</td>
<td>3</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td>Video</td>
<td>5</td>
<td>3</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td>street signage</td>
<td>7</td>
<td>1</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td>teacher/ lecturer</td>
<td>4</td>
<td>3</td>
<td>3.5</td>
<td>9</td>
</tr>
<tr>
<td>Parents</td>
<td>3</td>
<td>4</td>
<td>3.5</td>
<td>10</td>
</tr>
<tr>
<td>peer educator/counsellor</td>
<td>2</td>
<td>4</td>
<td>3</td>
<td>11</td>
</tr>
<tr>
<td>Posters</td>
<td>2</td>
<td>1</td>
<td>1.5</td>
<td>12</td>
</tr>
<tr>
<td>Internet</td>
<td>1</td>
<td>3</td>
<td>2</td>
<td>12</td>
</tr>
<tr>
<td>IEC materials</td>
<td>0.5</td>
<td>0</td>
<td>0.25</td>
<td>14</td>
</tr>
<tr>
<td>Theatre</td>
<td>0.5</td>
<td>0</td>
<td>0.25</td>
<td>14</td>
</tr>
<tr>
<td>Total</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td></td>
</tr>
</tbody>
</table>

On ranking the sources of information used by both PLHIV and the HCW, Television was ranked best at 13.5%, then radio 11%, followed by church/mosque/ synagogue at 9% and health care workers at 7.5%. Other sources with higher frequencies for both groups include civil society, newspapers and peers as shown in the figure 4.3.3 below. The health care workers tended to have higher frequencies of access to information through various sources than PLHIV as reflected in figure 4.3.3 below.
Chapter 5

This chapter deals with the investigation as to whether the PLHIV and the HCW know about the provision HIV related legal and policy documents that should guide the upholding of rights to privacy and confidentiality. This was measured through either having read or heard about the documents and institutions that contain the provisions of rights to privacy and confidentiality. The documents include chapter four of the Constitution of Kenya 2010, that contains the bill of rights, HIV & AIDS Prevention and Control Act 2006, National guidelines for HIV testing and counselling, Government policy on HIV and HIV training curriculum in Universities and colleges. The institution was the HIV and AIDS tribunal.

5.1 Level of awareness of the provisions of Chapter four of the constitution

When asked whether they had heard about chapter four of the constitution that contains the provisions on the right to privacy, 55% of the PLHIV respondents said “yes” and 45% declared they had not heard about it. 70% of the respondents declared they had not read the chapter of the constitution with the provisions on the right to privacy; only 30% acknowledged having read the chapter in the Constitution.

Figure 5.1.1 Respondents’ level of the provisions chapter four of the Kenyan Constitution

Further inquiry during the focus group revealed that even though 30% of the PLHIV claimed to have read the Constitution, none of them could correctly quote an article or a section of the Constitution that contains the provisions of rights to privacy and confidentiality.

Moderator: Do you know the chapter in the constitution that talks about human rights or rights to privacy and confidentiality?
Participant1: Chapter six
Participant2: Chapter six

Even though the PLHIV had read or heard the provisions of the constitution, they could not site the relevant articles, nor have an idea under which chapter the rights to privacy and confidentiality is under the constitution. When participants were asked about sources of information on the rights to privacy and confidentiality one of them in the FGD responded, “I have heard from the media but when am now told to quote, then I can’t quote anything”.

This shows that despite many PLHIV having heard about the constitution, they were unable to discuss any specific provisions. Among the health care workers (HCW), a higher percentage had heard about the constitution compared to those who had read. The HCW who had read the constitution were only 35% which is 5% higher than the PLHIV. This was the case despite having higher level of education than the PLHIV.

5.2. Level of awareness of the provisions HIV and AIDS Prevention and Control Act (HAPCA) 2006

While 80% of the HCW had heard about the HIV Prevention and Control act 2006, only 35% had read it. For the PLHIV, 35% read while 65% heard about the provisions of the document. According to figure 5.2.1 below, there is equal readership of the document between the PLHIV and HCW. There are generally low levels of awareness in both groups since those who have read the provisions of HIV Prevention and Control Act 2006 in both groups are less than half.

In the focus group discussions only five PLHIV out of the twenty six had heard the provisions of the documents. This shows low level of understanding of the term human rights.
Figure 5.3.1  Level of awareness of the provisions of National guidelines for testing and counselling

Only 40% of all the respondents had heard about the HIV tribunal. Both the PLHIV and the HCWs registered a score of 40% respectively when asked whether they had heard about the provisions of the HIV tribunal as shown in the figure 5.3.1 below. This institution registered the least level of awareness compared to the other documents as shown below.

Figure 5.4.1 Level of awareness of the provisions of HIV and AIDS tribunal

The least known item in the list is the HIV tribunal which only 40% of the respondents had heard about. The most popular/known document was the National guidelines for testing and counselling which 80% of the respondents had heard about and 55% had read.

5.5 Level of awareness of Government policy on HIV and AIDS (Kenya National AIDS Strategic Plan 2009/10 to 2012/13)

Half of the HCW respondents interviewed knew what the government policy on HIV was while the other half did not know. The PLHIV had 35% who knew what the government policy on HIV and AIDS is while 65% lacked knowledge on the same as shown in the figure 5.5.1 below.

Figure 5.5.1 Level of awareness of Government policy on HIV and AIDS

Only 40% of all the respondents had heard about the HIV tribunal. Both the PLHIV and the HCWs registered a score of 40% respectively when asked whether they had heard about the provisions of the HIV tribunal as shown in the figure 5.4.1 below. This institution registered the least level of awareness compared to the other documents as shown below.

Figure 5.6.1 Knowledge of policy in HIV training curriculum at the Medical Training institutions

The HCWs who knew about the policy in HIV training curriculum were almost equal to the PLHIV. The difference was 10% as 60% of the HCWs knew of the policy which only 50% of the PLHIV knew.

Table 5.3.1 Level of awareness of the provisions of National guidelines for testing and counselling

<table>
<thead>
<tr>
<th></th>
<th>HCW</th>
<th>PLHIV</th>
<th>Total %</th>
<th>Total %</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Heard</td>
<td>Read</td>
<td>Heard</td>
<td>Read</td>
</tr>
<tr>
<td>Yes %</td>
<td>95</td>
<td>70</td>
<td>70</td>
<td>40</td>
</tr>
<tr>
<td>No%</td>
<td>5</td>
<td>30</td>
<td>30</td>
<td>60</td>
</tr>
<tr>
<td>Total</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 5.2.1 Level of awareness of the provisions HIV and AIDS Prevention and Control Act 2006

<table>
<thead>
<tr>
<th></th>
<th>HCW</th>
<th>PLHIV</th>
<th>Total %</th>
<th>Total %</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Heard</td>
<td>Read</td>
<td>Heard</td>
<td>Read</td>
</tr>
<tr>
<td>Yes %</td>
<td>80</td>
<td>35</td>
<td>65</td>
<td>35</td>
</tr>
<tr>
<td>No%</td>
<td>20</td>
<td>65</td>
<td>35</td>
<td>65</td>
</tr>
<tr>
<td>Total</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
</tr>
</tbody>
</table>

5.3 Level of awareness of the provisions of National guidelines for testing and counselling

HCW and PLHIV interviewed had low level of awareness and knowledge of most of the documents they were interviewed about with the exception of the National guidelines for testing and counselling. 80% of the participants in the study had heard about its provisions and 55% having read the provisions. The health care workers were reported to be more aware of the provisions of this document than the PLHIV. While 95% of the HCW had heard about the provisions of this document, only 70% had read it. Among the PLHIV 70% had heard about the provisions and 40% had read the document as shown in the table 5.3.1 below.

Table 5.3.1 Level of awareness of the provisions of National guidelines for testing and counselling

<table>
<thead>
<tr>
<th></th>
<th>HCW</th>
<th>PLHIV</th>
<th>Total %</th>
<th>Total %</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Heard</td>
<td>Read</td>
<td>Heard</td>
<td>Read</td>
</tr>
<tr>
<td>Yes %</td>
<td>95</td>
<td>70</td>
<td>70</td>
<td>40</td>
</tr>
<tr>
<td>No%</td>
<td>5</td>
<td>30</td>
<td>30</td>
<td>60</td>
</tr>
<tr>
<td>Total</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
</tr>
</tbody>
</table>
5.7 Informants’ level of awareness of the provision of policy documents and institutions.

Ranking the level of awareness based on the nine items tested, there appeared to be generally low levels of awareness on rights to privacy and confidentiality among both the PLHIV and HCWs. 10% of HCWs and 40% of PLHIV were ranked to have very poor levels of awareness; 5% and 10% of PLHIV and HCWs respectively were ranked to be excellently aware of the provisions of the policy documents and institutions as shown in the figure below. 62.5% of the respondents were ranked between poor and average. Those ranked above average were 37.5%. The HCWs who were the most aware group had 50% from average and below as shown in the table 5.7.1 below.

Table 5.7.1  Informants’ level of awareness of the provision of policy documents and institutions.

<table>
<thead>
<tr>
<th>Rank</th>
<th>HCW %</th>
<th>Cumm %</th>
<th>PLHIV %</th>
<th>Cumm %</th>
<th>Total HCW and PLHIV %</th>
<th>Cumm %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very poor</td>
<td>10.0</td>
<td>10.0</td>
<td>40.0</td>
<td>25.0</td>
<td>40.0</td>
<td>25.0</td>
</tr>
<tr>
<td>Poor</td>
<td>5.0</td>
<td>15.0</td>
<td>15.0</td>
<td>5.0</td>
<td>30.0</td>
<td>30.0</td>
</tr>
<tr>
<td>Below average</td>
<td>15.0</td>
<td>30.0</td>
<td>20.0</td>
<td>65.0</td>
<td>17.5</td>
<td>47.5</td>
</tr>
<tr>
<td>Average</td>
<td>20.0</td>
<td>50.0</td>
<td>20.0</td>
<td>75.0</td>
<td>15.0</td>
<td>62.5</td>
</tr>
<tr>
<td>Good</td>
<td>30.0</td>
<td>80.0</td>
<td>45.0</td>
<td>80.0</td>
<td>17.5</td>
<td>80.0</td>
</tr>
<tr>
<td>Very good</td>
<td>15.0</td>
<td>95.0</td>
<td>10.0</td>
<td>90.0</td>
<td>12.5</td>
<td>92.5</td>
</tr>
<tr>
<td>Excellent</td>
<td>5.0</td>
<td>100.0</td>
<td>10.0</td>
<td>100.0</td>
<td>7.5</td>
<td>100.0</td>
</tr>
<tr>
<td>Total</td>
<td>100</td>
<td>100.0</td>
<td>100.0</td>
<td>100.0</td>
<td></td>
<td>100.0</td>
</tr>
</tbody>
</table>

Figure 5.7.1  Informants’ level of awareness of the provision of policy documents and institutions

As shown in the figure 5.7.1 above less than half of the respondents were ranked above average, PLHIV showing lower levels of understanding of provisions of the policy document. The HCW generally had higher levels of understanding of policy documents. This could be attributed to their level of education, nature of training and on job trainings and workshops.

5.8 Source of information on HIV and AIDS policy documents and institutions

The reported sources of information on policy documents and institutions include electronic media such as TV, radio, internet, video shows; print media such as brochures, magazines, newspapers; trainings such as seminars and workshops, educational institutions through teachings and lectures; health care facilities; and other sources such as VCT, work place, constitution, friends and civil society organizations.

Table 5.8.1  PLHIV’s Sources of information on HIV and AIDS policy documents and institutions

<table>
<thead>
<tr>
<th>Source of awareness</th>
<th>Chapter in the Kenyan constitution containing the Bill of rights (%)</th>
<th>HIV and AIDS Prevention and Control Act 2006 (%)</th>
<th>National Guidelines for Testing and counselling (%)</th>
<th>HIV and AIDS Tribunal (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Electronic media</td>
<td>29</td>
<td>55</td>
<td>23</td>
<td>34</td>
</tr>
<tr>
<td>Health care facility</td>
<td>36</td>
<td>0</td>
<td>38</td>
<td>22</td>
</tr>
<tr>
<td>Training, workshop/ seminar</td>
<td>14</td>
<td>9</td>
<td>8</td>
<td>11</td>
</tr>
<tr>
<td>Print media</td>
<td>7</td>
<td>9</td>
<td>8</td>
<td>11</td>
</tr>
<tr>
<td>Work place</td>
<td>7</td>
<td>9</td>
<td>8</td>
<td>11</td>
</tr>
<tr>
<td>Friends</td>
<td>7</td>
<td>9</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Civil society/ organizations</td>
<td>0</td>
<td>0</td>
<td>8</td>
<td>11</td>
</tr>
<tr>
<td>Church</td>
<td>0</td>
<td>0</td>
<td>7</td>
<td>0</td>
</tr>
</tbody>
</table>

Table 5.8.2  HCW’s Sources of information on HIV and AIDS policy documents and institutions

<table>
<thead>
<tr>
<th>Source of awareness</th>
<th>Chapter in the Kenyan constitution containing the Bill of rights (%)</th>
<th>HIV and AIDS Prevention and Control Act 2006 (%)</th>
<th>National Guidelines for Testing and counselling (%)</th>
<th>HIV and AIDS Tribunal (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Training/seminar/ workshop</td>
<td>44</td>
<td>62</td>
<td>61</td>
<td>50</td>
</tr>
<tr>
<td>School/ college lec- turer</td>
<td>19</td>
<td>19</td>
<td>19</td>
<td>12</td>
</tr>
<tr>
<td>Electronic media</td>
<td>13</td>
<td>13</td>
<td>0</td>
<td>25</td>
</tr>
<tr>
<td>Print media</td>
<td>25</td>
<td>0</td>
<td>6</td>
<td>13</td>
</tr>
<tr>
<td>Health care facility</td>
<td>0</td>
<td>0</td>
<td>17</td>
<td>0</td>
</tr>
<tr>
<td>VCT</td>
<td>0</td>
<td>0</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>Work place</td>
<td>6</td>
<td>6</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Constitution</td>
<td>12</td>
<td>12</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

While the PLHIV accessed most their information about policy documents through electronic media, a majority of the HCW accessed their information about the provisions of documents through trainings, seminars and workshops as shown in table 5.8.1 and 5.8.2 above.

Based on the above findings, the source of information is likely to contribute to the level of awareness of the provisions of legal policy documents. This is because the HCW who had most of their sources from trainings, seminars and workshops had a higher level of awareness compared to those accesses such from electronic media. This could be because the electronic media has only one way communication while the seminars and workshops are two way and allows for questions and discussions.
6.1 Human rights violation

Under this section, the respondents were asked about their understanding of the term ‘violation of human rights’. Most PLHIV equated human rights violation with going against the rights of the PLHIV’s. 20% gave statements such as ‘discrimination because of status’, and while 5% indicated ‘abusing those who are HIV positive’.

20% of PLHIV respondents did not understand what the term meant. Some had not even heard about it. Another 30% understood human rights violation as going against someone’s rights/denying one his/her rights/entitlements as shown in the table below

<table>
<thead>
<tr>
<th>Respondents’ definition</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Going against someone’s rights/ denying one his/her rights/ entitlements</td>
<td>30</td>
</tr>
<tr>
<td>Do not know/ don’t understand/ never heard</td>
<td>20</td>
</tr>
<tr>
<td>Discrimination based on status (e.g. denying one employment, refusing to sit with PLHIV)</td>
<td>20</td>
</tr>
<tr>
<td>Abusing those who are HIV positive</td>
<td>5</td>
</tr>
<tr>
<td>Telling others about me without my consent</td>
<td>5</td>
</tr>
<tr>
<td>Denial of necessities like attending clinic for PLHIV</td>
<td>5</td>
</tr>
<tr>
<td>It entails gender based violence without any due reason</td>
<td>5</td>
</tr>
<tr>
<td>Inflicting psychological, physical or emotional harm to others</td>
<td>5</td>
</tr>
<tr>
<td>To forbid someone from doing something he/she feels is right</td>
<td>5</td>
</tr>
</tbody>
</table>

45% of the HCW understood human rights violation as going against an individual’s entitlements. 15% defined it as Discrimination because of one’s HIV status, race, sexuality and other conditions, while 10% perceived it as going against a person’s dignity or wish. Another 10% described it as interfering with someone’s privacy. There was however a proportion 5% who defined it as depriving ones privileges as shown in table 6.1.2 below.
In the FGDs human rights violation was defined as ‘when rights one is entitled to as a human being are interfered with without one’s consent’.

### Participant 1: Human rights violation is when those rights that are entitled to you as a human being are interfered with without your consent.

### Participant 2: You find that someone attacks a person and he goes against the will of the individual. In that particular case, they have violated the rights of that particular individual.

While the understanding of the term ‘violation of human rights’ was generally low, the HCW had a better understanding than the PLHIV. Apart from one HCW who understood human rights violation as ‘depriving one’s privileges’, the rest had a rough idea. 20% of the PLHIV on the other hand had confessed to neither knowing nor understanding human rights violation. The disparity in the levels of understanding between the HCWs and the PLHIV can be linked to the levels of education and access to information about human rights of the PLHIV and HCW. Low level/lack of formal education is likely to lead to inability to read and understand policy documents dealing with rights.

**6.2 Breach of rights to privacy within the Health care facility**

This section was focused on the breach of rights to privacy and confidentiality within the health care setting by HCWs. As reported in the study, 35% of the HCWs had disclosed a person’s HIV status without their consent while the rest had not. The reasons they were unable to obtain their consents include: 25% were in denial/refused but needed to get further assistance either from other family members or care givers; 13% had mental disability; 12% were below 18 years of age [minors] and 50% were unconscious as shown in figure 6.2.1 below.

![Figure 6.2.1 Reasons for inability of HCW to obtain consent from PLHIV](image)

In the FGD all the HCW agreed that there are cases of breach of rights to privacy within the Health care setting. HCW reported having encountered issues surrounding the disclosure of a person’s HIV status without their consent. Such cases presented include when the care giver discuss the patient’s status with the PLHIV, when the patient is a minor and the guardian shares the status with the HCW without seeking the consent of the minor.

There is breach of rights to privacy and confidentiality within the health care setting. The breach when the HCW reveal the HIV status of PLHIV without their consent. The victims of breach of rights to privacy reported include minors, unconscious patients, those with mental disability and those who needed further help. The breach occurs due to either lack of or inadequate knowledge on rights to privacy and confidentiality.

Most PLHIV in the FGD also felt that the isolated location of the Comprehensive Care Centre contributes to breach of their rights to privacy since it is isolated and everyone seen there is assumed to be positive.

**Table 6.1.2 HCW’s understanding of human rights violation.**

<table>
<thead>
<tr>
<th>Respondents definition</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Denials of rights/ Going against the rights of other persons/ Going against what one is entitled to/ infringing peoples’ rights</td>
<td>45</td>
</tr>
<tr>
<td>Discrimination because of my HIV status, race, sexuality and other conditions</td>
<td>15</td>
</tr>
<tr>
<td>Going against a person’s dignity and wish</td>
<td>10</td>
</tr>
<tr>
<td>Going against/ interfering with one’s privacy</td>
<td>10</td>
</tr>
<tr>
<td>Failure to inform me on what is being done to me or to ask for my opinion</td>
<td>5</td>
</tr>
<tr>
<td>Going against the law or human rights</td>
<td>5</td>
</tr>
<tr>
<td>Imposing your own values on others</td>
<td>5</td>
</tr>
<tr>
<td>Depriving one’s privileges</td>
<td>5</td>
</tr>
</tbody>
</table>

**6.3 Circumstances for disclosure of PLHIV’s status without consent**

The HCWs indicated that there are situations/circumstances when they are allowed to disclose one status without the individual’s consent and these circumstances were mentioned as indicated in the table below.

**Table 6.3.1 Circumstances for disclosure of PLHIV’s status without consent**

<table>
<thead>
<tr>
<th>Circumstance</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>If the person has mental disability and the legal guardian gives consent</td>
<td>23</td>
</tr>
<tr>
<td>When it is in the best interest of the patient</td>
<td>21</td>
</tr>
<tr>
<td>When a person gives his written consent</td>
<td>19</td>
</tr>
<tr>
<td>If the person is a child and the guardian gives consent</td>
<td>15</td>
</tr>
<tr>
<td>If the court requires the information</td>
<td>10</td>
</tr>
<tr>
<td>For purposes of epidemiological study/research</td>
<td>7</td>
</tr>
<tr>
<td>When the person is unconscious and needs a caregiver</td>
<td>5</td>
</tr>
</tbody>
</table>

Other circumstances mentioned in the FGD include when the patient is in denial, when the patient too ill and needs Diagnostic Testing and Counseling (DTC) and when there is need to disclose to the partner.

Some of the reasons given above can spark a debate while others indicate inadequate knowledge of policy documents on the side of HCW. When one talks of ‘the best interest of the patient’, it becomes prudent to ask who determines the best interest of the patient. The so called the best interest of the patient could be against the patient’s will in such a case, is it still the interest of the patient.

[Figure 6.3.1 Circumstances when HCW is allowed to disclose the HIV status of individuals without their consent](image)
This involved asking whether there are institutions that require HCWs to disclose a person's HIV status when they receive treatment in their facility. Based on the report 60% of the HCWs reported that there are institutions that require the health care workers to disclose a persons' HIV status without their consent as shown below.

This shows that there are situations when the cases of breach of rights to privacy and confidentiality are a requirement of other institutions such as potential employers, insurance companies among others.

There is therefore need for a public campaign on the policy requirements for upholding rights to privacy and confidentiality through the media to inform the entire public inclusive of the potential employers on policy requirements. This will increase the general awareness of rights to privacy and confidentiality and hence reduce cases of breach from without the health care setting.

Figure 6.4.1 Breach of rights to privacy and confidentiality through institutional requirements

Breach of rights to privacy through HIV and AIDS Information storage

This section inquired whether the PLHIV and the HCW are aware of the policy requirements and guidelines for HIV and AIDS information storage. The HCWs reported that there are safeguards in place to ensure privacy and confidentiality of the health care information system. Some of the safeguarding measures mentioned include Password, ethics act, records being restricted to handling by HCW alone and information being coded to conceal identity. Proper filing system and restriction of staff from access was also mentioned. When the HCW were asked whether there are policy guidelines on storing HIV and AIDS information within the facility, 76% responded 'yes' while 26% said "no".

The PLHIV on the other hand expressed lack of knowledge as to whether their health care providers have a safe way of keeping information/data about their HIV status. When asked about the safety measures in place to uphold their privacy within the health care setting one of the PLHIV had this to say in the FGD.

"In that case, it is the doctor who treats you who knows the safety measures they have in place, because they are the ones who hold your file and it ends there, and I believe from the time you are treated to the time the file is taken to the archives it shall have passed so many hands."

Other respondents advised that the information on their HIV status should be kept in electronic data (computer) under secret password only known by the health care provider in charge.

To safeguard the information, passwords should be put in place so that unless you have the password you cannot access the information. With this the information will be safeguarded.

The respondents especially the PLHIV reported lack of knowledge on policy issues about storage HIV and AIDS information while 26% of HCW reported lack of policy guidelines for HIV and AIDS data storage. This could be due to inadequate awareness of policy guidelines for HIV data storage within the health care setting or a complete lack of policy guidelines. It therefore means that the 26% are either not aware of the existence of policy guidelines on HIV and AIDS data storage or there is complete lack of policy guidelines for data storage. This would by extension mean that data storage policy guidelines are not exercised if they exist and or that they are not publicised or are not being implemented to allow for adequate knowledge by both the HCW and PLHIV.

This calls for a training of the HCWs on the policy provisions for HIV and AIDS data storage in a bid to uphold the PLHIV’s rights to privacy and confidentiality. There is need to create awareness among the PLHIV by sensitising them on the standard procedures of handling HIV and AIDS data and information how this data is being managed and used.

6.6 Breach of rights to privacy as reported at PLHIV level

This targeted the reports from the PLHIV on whether their rights to privacy and confidentiality had been breached. While 20% of the PLHIV had their status disclosed without their consent, 10% did not know whether their status had been disclosed and 70% had their HIV status undisclosed to anyone without their consent.

The cases of breach of rights to privacy and confidentiality reported by the PLHIV indicated that 20% of the PLHIV have experienced breach to rights to privacy and confidentiality.

Despite breach of rights to privacy and confidentiality, 80% of the PLHIV respondents still felt and agreed that there are circumstances when their HIV status could be shared. However, 15% felt that their status should not be shared despite the circumstances and 5% did not know whether there are such circumstances or not. 70% of the PLHIV who could share their status felt that their status should not be shared despite the circumstances when their HIV status could be shared. However, 15% responded that they are not aware of the existence of policy guidelines on how and where and how to report cases of breach of rights to privacy and confidentiality.

From the findings, it is evident that breach of rights to privacy and confidentiality does not only take place within the health care setting but also within other institutions including the Family and insurance companies. It was however noted that not all the respondents whose rights to privacy were breached did not report the issue because. Reasons given for not reporting include: One respondent (25%) did not know it was a right; two respondents (50%) had just been discharged and did not know where and how to start the process and one (25%) was in ICU at the time of disclosure hence could not take action.

This presents a need for training on rights to privacy and confidentiality and advocacy for the rights of the weak patients. There is also need to train the PLHIV on the procedures of where and how to report cases of breach of rights to privacy and confidentiality.

This calls for a training of the HCWs on the policy provisions for HIV and AIDS data storage in a bid to uphold the PLHIV’s rights to privacy and confidentiality. There is need to create awareness among the PLHIV by sensitising them on the standard procedures of handling HIV and AIDS data and information how this data is being managed and used.
The respondents willing to share their status felt that at one point or the other they may need help from someone who must know their HIV and AIDS status. There is therefore need to sensitize care givers, family members and the entire public on issues of rights to privacy and confidentiality so that sharing of one’s status may not lead to breach to rights to privacy and confidentiality.

6.7.1 Adolescent’s rights to privacy

When asked whether the adolescents should have the rights to privacy of their HIV status, 85% responded “yes” and 15% “no.”

When asked whether the lack of rights to privacy of the adolescents’ HIV status restrict their access to service or the liberty of HCWs in offering services to the adolescents, the answers were as follows:

This shows that the rights to privacy and confidentiality needs to be upheld to enable them access health care services without fear of discrimination or stigma.
Breach Of Rights To Privacy Resulting From Stigma

Chapter 7

7.1 Perception/understanding of the term stigma

Stigma was defined differently by different respondents. While 30% understood stigma as a negative feeling of being belittled, isolated, victimized/rejected or discriminated because of a condition, 25% understood it as negative/unfair treatment because of one’s condition. Others 5% talked of self-denial.

The responses given reflected two broad categories of stigma; stigma initiated by others and self-initiated stigma. 30% of the respondents, identified stigma as a negative feeling of being belittled isolated, victimized/rejected/ discriminated because of a condition. Other respondents referred to stigma as something caused by others.

<table>
<thead>
<tr>
<th>Table 7.1.1 Understanding of the term ‘stigma’</th>
</tr>
</thead>
<tbody>
<tr>
<td>Response</td>
</tr>
<tr>
<td>Negative feeling of being belittled isolated, victimized/rejected/ discriminated because of a condition</td>
</tr>
<tr>
<td>Negative/unfair treatment because of one’s condition</td>
</tr>
<tr>
<td>Being feared/isolated/deserted by people</td>
</tr>
<tr>
<td>An in-fear of disclosing and one knowing of one’s status</td>
</tr>
<tr>
<td>Being looked down upon</td>
</tr>
<tr>
<td>Doing things that degrade somebody negatively</td>
</tr>
<tr>
<td>Label given to PLHIV that tends to judge them on basis of health status</td>
</tr>
<tr>
<td>Looking down upon someone/undermining them because of the state they are in</td>
</tr>
<tr>
<td>Psychological torture inflicted on a human being by other people through talking about him/can be self-inflicted</td>
</tr>
<tr>
<td>Self-denial</td>
</tr>
</tbody>
</table>

From the perception/understanding, it was clear that most PLHIV know what stigma is. The definitions given in the FGD revolved around rejection/negative treatment because of an individual’s HIV status and the psychological torture that comes with the same.

In the FGDs the perception revolved around negative treatment and discrimination based on one’s status. It was also perceived as psychological torture that one receives when treated negatively.

Participant1: Stigma is being discriminated based on your status by other people who are around you who behave in a manner that makes you feel you are not liked.

Participant2: It is when I am treated like an outcast because I am not like the rest because of my status, and this fear is what makes people not to disclose their status due to stigma.

Participant3: It also psychological torture, i.e. if you are going to greet somebody he/she withdraws the hand, you feel humiliated the way this colleague explained.
The PLHIV felt that the fear of stigmatization makes many of their colleagues fear to disclose their status to others who are not living with HIV and AIDS as shown in the excerpt above. There was also an idea that stigma could be self-initiated through self-withdrawal or personal feelings by the PLHIV themselves.

Participant: Some are initiated by ourselves depending on the situation, like you may be passing somewhere and knowing your status—maybe you are ailing a little, and so when somebody looks at you, what comes into your mind is the fact that the person knows that you are sick and so the stigma comes in, yet the person could be admiring or appreciating you.

Participant: At times just by the fact that you are thin, you will feel stigmatized when you meet others because you see yourself unlike them.

### 7.2 Main contributor to stigma

The work place was the leading contributor to stigma at 35% (Thirty five percent) followed by the family at 23% (Twenty three percent), insurance companies at 19% (Nineteen percent), and health facilities at 14% (Fourteen percent) and finally policy makers at 9% (Nine percent) as shown in the diagram below.

Stigma was recognized to be common at the work place and the PLHIV gave several situations when they have been stigmatized at work place. One of the PLHIV for instance gave this example of stigmatization at her work place.

Participant: At the work place just in Kenyatta Hospital, we used to have tea together for the purpose of reducing stigma, during the process, the other staff members who were HIV negative stopped using the cups we were using and they would use their own cups, but because actions speak louder than words, to me I felt that was stigma.

### 7.3 Stigma and violence as a result of disclosure

Disclosure of a person’s HIV status was mentioned as one of the key contributors to stigma. The PLHIV who have faced violence or some kind of stigma as a result of their status being disclosed were 30%. This shows that a good percentage is stigmatized when their status is disclosed without their consent.

The nature of violence or stigma faced by the individuals whose statuses were disclosed without consent includes psychological violence; insult, spitting, continuous humiliation and being ignored as shown in figure 6.8.1 below.

### 7.4 Socio-economic factors privacy and Health seeking behaviour

As reported in the study, 85% (Eighty five percent) of health care workers seek to know the socio-economic backgrounds of those who seek HIV related care while 15% (Fifteen percent) don’t. Though the 15% (Fifteen percent) gave no reasons for not seeking to know the socio-economic background of PLHIV, the 85% (Eighty five percent) mentioned several reasons listed below.

- HIV patients require frequent visits to the health care center and therefore require funds
- HIV patients require comprehensive treatment including medication, nutrition and hygiene and all these require funds
- Assessing if the patient can access basic needs
- To ascertain the level of risks a patient is exposed to during risk assessment at a VCT For purposes of psychosocial support

In addition, 90% (Ninety percent) of the HCWs thought that the economic status of the patients influenced their care seeking behaviour and should be known in order to advise them appropriately.
Chapter 8

8.1 Level of understanding of human rights and rights to privacy in relation to HIV

The understanding of the term “human right” was different among the two different groups of people, though the respondents had a general understanding ranging from entitlements to freedom to access basic needs and services. A good number of PLHIV (25 percent) perceived human rights in terms of freedom to live while a good number (20 percent) of HCW perceived it in terms of acting without causing harm to others as shown in table 4.1.1 and 4.1.2 respectively. This suggests that everyone is likely to understand human rights based on his position, role or profession.

Some HCW understood human rights as “Privileges that one needs to have to continue living well”. This shows a complete lack of understanding of the human rights. When human rights are misunderstood as privileges by the health care workers, then little may be done to prevent breach of rights to privacy and confidentiality in a health care setting. Others perceived human rights as protective; others saw it as a tool for equity and equality. In general, human rights was perceived in many ways and equated to different things such as: to be loved, to live with HIV, to access services openly, to acquire basic needs, to cause no harm to others, privileges and to others it meant to do the right thing.

As noted by Pritts (22), human rights mean different things to different people and as such should be contextualized before defining.

From the study it appears that rights to privacy is understood and experienced on a personal level and often means different things to different people. This is also noted by Lowrance (23) and Pritts (24). In modern society, the term “privacy” is used to denote different, but overlapping, concepts such as the right to bodily integrity or to be free from intrusive searches or surveillance. The concept of privacy is also context specific, and acquires a different meaning depending on the stated reasons for the information being gathered, the intentions of the parties involved, as well as the politics, convention and cultural expectations (25).

The study generally presents a basic understanding of human rights and rights to privacy and confidentiality among both PLHIV and HCW. While basic understanding of privacy, confidentiality and violation of human rights is essential, it may not be effective in reducing breach of rights to privacy. As noted by Lowrence (26), correct and precise knowledge of rights to privacy and confidentiality is essential for the realization of human rights to privacy and confidentiality.

The low level of understanding the human rights and rights to privacy and confidentiality is subject to the level of education, medium of information and professional requirements that predispose one to uphold rights privacy and confidentiality or to implement human rights policies.

Most study participants received information in relaxed informal environments and media such as TV, radio, churches friends and peers. This could mean that the policy documents on human rights and rights to privacy are either not accessible within the hospital setting or that the HCWs and PLHIV lacked the motivation to know their rights.

As noted by Pritts (22), human rights mean different things to different people and as such should be contextualized before defining.

From the study it appears that rights to privacy is understood and experienced on a personal level and often means different things to different people. This is also noted by Lowrance (23) and Pritts (24). In modern society, the term “privacy” is used to denote different, but overlapping, concepts such as the right to bodily integrity or to be free from intrusive searches or surveillance. The concept of privacy is also context specific, and acquires a different meaning depending on the stated reasons for the information being gathered, the intentions of the parties involved, as well as the politics, convention and cultural expectations (25).

The study generally presents a basic understanding of human rights and rights to privacy and confidentiality among both PLHIV and HCW. While basic understanding of privacy, confidentiality and violation of human rights is essential, it may not be effective in reducing breach of rights to privacy. As noted by Lowrence (26), correct and precise knowledge of rights to privacy and confidentiality is essential for the realization of human rights to privacy and confidentiality.

The low level of understanding the human rights and rights to privacy and confidentiality is subject to the level of education, medium of information and professional requirements that predispose one to uphold rights privacy and confidentiality or to implement human rights policies.

Most study participants received information in relaxed informal environments and media such as TV, radio, churches friends and peers. This could mean that the policy documents on human rights and rights to privacy are either not accessible within the hospital setting or that the HCWs and PLHIV lacked the motivation to know their rights.

As noted by Pritts (22), human rights mean different things to different people and as such should be contextualized before defining.

From the study it appears that rights to privacy is understood and experienced on a personal level and often means different things to different people. This is also noted by Lowrance (23) and Pritts (24). In modern society, the term “privacy” is used to denote different, but overlapping, concepts such as the right to bodily integrity or to be free from intrusive searches or surveillance. The concept of privacy is also context specific, and acquires a different meaning depending on the stated reasons for the information being gathered, the intentions of the parties involved, as well as the politics, convention and cultural expectations (25).

The study generally presents a basic understanding of human rights and rights to privacy and confidentiality among both PLHIV and HCW. While basic understanding of privacy, confidentiality and violation of human rights is essential, it may not be effective in reducing breach of rights to privacy. As noted by Lowrence (26), correct and precise knowledge of rights to privacy and confidentiality is essential for the realization of human rights to privacy and confidentiality.

The low level of understanding the human rights and rights to privacy and confidentiality is subject to the level of education, medium of information and professional requirements that predispose one to uphold rights privacy and confidentiality or to implement human rights policies.

Most study participants received information in relaxed informal environments and media such as TV, radio, churches friends and peers. This could mean that the policy documents on human rights and rights to privacy are either not accessible within the hospital setting or that the HCWs and PLHIV lacked the motivation to know their rights.

As noted by Pritts (22), human rights mean different things to different people and as such should be contextualized before defining.

From the study it appears that rights to privacy is understood and experienced on a personal level and often means different things to different people. This is also noted by Lowrance (23) and Pritts (24). In modern society, the term “privacy” is used to denote different, but overlapping, concepts such as the right to bodily integrity or to be free from intrusive searches or surveillance. The concept of privacy is also context specific, and acquires a different meaning depending on the stated reasons for the information being gathered, the intentions of the parties involved, as well as the politics, convention and cultural expectations (25).

The study generally presents a basic understanding of human rights and rights to privacy and confidentiality among both PLHIV and HCW. While basic understanding of privacy, confidentiality and violation of human rights is essential, it may not be effective in reducing breach of rights to privacy. As noted by Lowrence (26), correct and precise knowledge of rights to privacy and confidentiality is essential for the realization of human rights to privacy and confidentiality.

The low level of understanding the human rights and rights to privacy and confidentiality is subject to the level of education, medium of information and professional requirements that predispose one to uphold rights privacy and confidentiality or to implement human rights policies.

Most study participants received information in relaxed informal environments and media such as TV, radio, churches friends and peers. This could mean that the policy documents on human rights and rights to privacy are either not accessible within the hospital setting or that the HCWs and PLHIV lacked the motivation to know their rights.
As noted by Pritts, high value should be placed on protecting the privacy, confidentiality, and security of PLHIV health information as a way of upholding their rights. This is because privacy is a basic human right, and confidentiality and security are critical in upholding rights to privacy and confidentiality.

Respecting privacy (and autonomy) is a form of recognition of the attributes that give humans their moral uniqueness. Indeed, privacy is valuable because it facilitates or promotes other fundamental values, including ideals of personhood such as: personal autonomy (the ability to make personal decisions); individuality, respect, dignity and worth as human beings.

Furthermore, ensuring privacy can promote more effective communication between physician and patient, which is essential for quality healthcare that is ethically expected of them. However, the implementation of policies means that they are unable to uphold their rights to privacy, confidentiality, and security of health information. In the clinical setting, breach of rights to privacy occur through lack of understanding of job applicants and current employees, and seeking to avoid discrimination, embarrassment, and harm. In the workplace, breach of rights to privacy occurs through the overheard communication between physician and patient, which is essential for quality healthcare that is ethically expected of them.

Another factor that could contribute to low level of awareness among the PLHIV are their sources of information. A number of the PLHIV got the information from one way channels of communication such as TV and radio. This means that they overheard and did not take part in the mainstream discussion. There is therefore need to train community health care workers on the content of these documents so that they can train the community members.

Most HIV clinic either heard or read the policy documents in a seminar, training, workshop or through lectures, this together with the higher literacy levels made them have a higher level of understanding compared to the PLHIVs. It was however noted that there level of understanding was generally very low. Less than half of the study participants 37.5% (Thirty seven point five percent) were ranked above average with only 7.5% (Seven point five percent) being excellent. Though the most study participants were aware of the policy documents most of them had not read them and lacked the knowledge about the provisions and contents of the policy documents and provisions. It therefore follows that there is inadequate knowledge of policy provisions for PLHIV and HCWs. This can pose a great threat to attaining the rights and confidentiality of the PLHIV, because the PLHIV cannot advocate for rights whose provisions they know not while on the other hand the HCWW cannot as well uphold such rights if they have not read or are unaware of the provisions for such.

In simple terms, those without the knowledge of provisions for their rights can’t identify when their rights are violated and hence cannot take any action to advocate for the same. In addition, lack of or inadequate knowledge about the provisions of policy documents among HCWs who are tasked with the responsibility of implementing policies means that they are unable to uphold the rights of PLHIV to privacy and hence fail to provide professional and quality healthcare that is ethically expected of them.

Though a good number (more than half) of the participants reported to have heard about the provisions of the policy documents, they had not read them and could neither quote nor article from the policies because the quality education, as an essential component of human well-being.

Breach of the rights to privacy and confidentiality were reported in the study term of disclosure of patient’s status without consent, HIV testing without the patient’s consent, and confidentiality of PLHIV’s HIV status without consent.

Concerning breach of rights to privacy and confidentiality within the health care setting, 35% (Thirty five percent) of the HCWs reported having disclosed PLHIV’s HIV status without their consent, while 20% (Twenty percent) of the PLHIV reported having had their status disclosed by HCWs without their consent. Such breach of rights within the health care settings can lead to stigma and may affect a patient’s ability and willingness to take up HIV related services including lifesaving treatment from the health care facility. Comprehensive HIV services should therefore factor in the clients’ needs and relevant personal circumstances and should monitor whether the HCWs implement the policy requirements in upholding PLHIV’s rights to privacy and confidentiality.

8.3 Breach of the right to privacy and confidentiality in relation to HIV

According to the International Guidelines on HIV/AIDS and Human Rights, it is, fundamental that person living with HIV and those with a clinical diagnosis of AIDS control access to their personal health information. Persons living with HIV have a right to: decide to whom, when, how, and to what extent they will disclose their personal health information; control the use and disclosure of their personal health information, and who has access to that information; and know how their personal information is going to be used and safeguarded.

Breaches of rights to privacy and confidentiality were reported in the study term of disclosure of patient’s status without consent, HIV testing without the patient’s consent, and confidentiality of PLHIV’s HIV status without consent.

Concerning breach of rights to privacy and confidentiality within the health care setting, 35% (Thirty five percent) of the HCWs reported having disclosed PLHIV’s HIV status without their consent, while 20% (Twenty percent) of the PLHIV reported having had their status disclosed by HCWs without their consent. Such breach of rights within the health care settings can lead to stigma and may affect a patient’s ability and willingness to take up HIV related services including lifesaving treatment from the health care facility. Comprehensive HIV services should therefore factor in the clients’ needs and relevant personal circumstances and should monitor whether the HCWs implement the policy requirements in upholding PLHIV’s rights to privacy and confidentiality.

Thorough mandatory testing for HIV without informed consent is unconstitutional, as it violates rights to privacy and confidentiality (Article 31 (c), and rights to protection of security of the person and freedom from degrading treatment and psychological torture (Articles 29A, 6d, and 11), as well as rights for respect for the inherent dignity of all human beings (Article 28). There are reported cases by the PLHIV where expectant mothers are compelled to undergo HIV tests when they seek pre natal care and services. There are also incidences when persons seeking testing services compelled to be accompanied by their sexual partners as a pre-condition to the service. Such cases contribute to the cases in which ones status is disclosed without their consent or such consent is achieved through coercion, intimidation and undue influence of the present partner. This may lead to domestic violence especially when one of the partners test positive and the other negative.

Of all cases of breach of rights to privacy and confidentiality none was reported and hence no one reported any action being taken against violators of rights to privacy and confidentiality. The reason given for not taking action included lack of knowledge on the procedure, some lacked the knowledge as to whether their rights were violated others were still admitted in hospital and were too weak to take any action.

In the PLHIV FDG some talked of lack of money while another said her religion (Christianity) required that she forgive. Breaches of rights to privacy and confidentiality were reported to lead to stigma and gender based violence with the women being the main victims. Though certain aspects of stigma were reported to be self initiated, a number (30%) of the PLHIV faced violence or some kind of stigma as a result of their status being disclosed.

This shows that a good percentage are stigmatized when their statuses are disclosed without their consent. It therefore follows that when the privacy rights of people living with HIV are not protected and respected, the impact of the epidemic on individuals and communities is worse.
A breach of the right to privacy often leads to breaches of other human rights, such as the right to liberty, security of the person, the right to work, and free choice of employment, and the right to adequate housing and medical care.

When the privacy of medical information is put at risk, the ability to reduce health risks, ensure early detection of illnesses, and ensure that patients receive appropriate medical treatment is weakened. As a result, people become reluctant to seek HIV testing and counselling if they believe their HIV status will be disclosed without consent to employers, insurance companies, the government, and relatives. Consequently, if fewer people find out that they are HIV-positive through testing (accompanied by appropriate pre- and post-test counselling), the risk of further HIV transmission is increased.

In summary, there is breach of rights to privacy and confidentiality both within and without the health care setting. The breach is due to inadequate knowledge of policy provisions on rights to privacy and confidentiality. It is also caused by inadequate knowledge on proper data storage and management procedures as well as ignorance of the PLHIV on how their data is handled. This calls for quick intervention in training HCW and members of the public on the policy provisions for rights to privacy and confidentiality.

The disclosure of personal information may cause intrinsic harm simply because that private information is known by others 39. As Gostin 35, notes, disclosure of information about HIV can reveal intimate details about an individual’s health status and other personal information that an individual may wish to keep private. Disclosures of HIV status can damage the privacy of persons living with HIV or AIDS and have other negative consequences such as stigma, discrimination, violence, and social isolation. Disclosure may also lead to serious economic harm, including loss of employment, insurance, or housing. On the other hand, disclosure of information about HIV may be required for public health surveillance, for the provision of appropriate medical care, and for certain non-health purposes such as law enforcement or insurance. Hence, the PLHIV and HCW need to be trained on laws and policies that balance the need for disclosure of HIV information with the protection of the privacy and autonomy of individuals with respect to their HIV status.

8.4 Breach of rights to privacy and HIV and AIDS related stigma

As noted in the study, breach of rights to privacy of PLHIV may lead to intolerance and exacerbate stigma or violence. Regular stigma or stigmatizing environment undermines public health efforts to identify persons HIV-positive for the purposes of prevention of transmission, and provision of care and treatment. If individuals fear the personal, social, and economic consequences of being diagnosed with HIV, they may forego testing, fail to discuss their health and risk behaviors with counselors, health care professionals, and their partners, and refrain from entering the health care system for treatment.39

Stigma toward people living with HIV has had a devastating impact on the HIV epidemic. The World Health Organization cites fear of stigma and discrimination as the main reason why people are reluctant to be tested, to disclose their HIV status or to take antiretroviral drugs 40. Social science researchers generally agree that HIV/AIDS-related stigma undermines public health efforts to combat the epidemic 41 (Brown et al. 2001).

AIDS stigma negatively affects preventive behaviors such as condom use, submitting to HIV testing, and seeking appropriate care following diagnosis, to name a few 40 (Brown et al. 2001). This stigma also diminishes the quality of care given to HIV positive patients and the perception and treatment of PLHIV by their communities, families, and partners 41 (Brown et al. 2001). Decreasing HIV-related stigma is a vital step in stemming the epidemic.

---

41 Ibid
Chapter 9

Summary, Conclusion and Recommendations

There is low level of awareness of policy provisions and documents leading to inadequate understanding of human rights, rights to privacy and violation of human rights among both the PLHIV and HCW. This contributes to increased breach of rights to privacy and confidentiality of the PLHIV both within the health care setting and outside.

The breach of rights to privacy and confidentiality has led to stigma and gender-based violence. Amidst such violence and stigma, there is a need for training these community leaders to identify the human rights violations and refer them appropriately, as well as ensure that the informal justice sector respects the Constitution of Kenya 2010 and the Bill of Rights, and produces outcomes that promote the rights of PLHIV.

9.1 Recommendations

9.1.1 Community Education

Based on the low level understanding of human rights and rights to privacy and confidentiality amongst the study respondents, there is a need to meaningfully engage with communities to provide information and promote discussions around:

- The legal meaning of human rights, privacy and human rights violations and their understanding and application of the same
- How breach of rights to privacy leads to stigma
- The content of the Constitution 2010 including the Bill of Rights
- The content of the HIV & AIDS Prevention & Control Act

9.1.2 Organize periodic consultative forum between PLHIV and HCWs

Given the documented PLHIV perception on breach of rights to privacy and confidentiality, it is critical that a relationship of trust, based on the duty of confidentiality, exists between PLHIV and HCWs. This can be achieved through periodic consultative meetings between PLHIV and HCWs. Without this relationship of trust, PLHIV will not be able to fully realize their right to access health-care and social services.
Given the human rights violations reported by the study participants at the hands of service providers within the health care setting, there is a need to engage with HCW to equip them with the knowledge to identify and address the kind of human rights violations and breaches of rights suffered by PLHIV, with emphasis on those breaches as a result of disclosure of rights to privacy and confidentiality.

HCW need to be trained on the rights of PLHIV, with particular regard to the right to privacy and confidentiality of their medical condition and information and the legal and policy framework in place. Since HCWs are often the first point of contact for PLHIV, they also need to be trained regarding when to refer patients for legal advice, and who to refer them to.

Since the work place was identified as the leading source of stigma, to prevent discrimination and resulting stigma at the workplace, employers should be educated regarding the legal framework related to the rights of PLHIV, with particular regard to issues related to stigma prevention, discrimination in the workplace, and in recruitment and retention policies.

Targeted Information and Communication

Many of the participants demonstrated an understanding of the existence of human rights legislation offering protection to PLHIV, but they were not aware of the details, which suggest that previous media campaigns to raise awareness on these issues have not so far reached the target populations or have not been well received or understood. There is, therefore, a need to ensure that the channels or mediums of communication to reach PLHIV are not only accessible, but also suitable and easy to comprehend and retain by the target population.

Printed information educational and communication materials should be produced in a simple format and language relevant to the communities and with possible translation capabilities into local languages and suited to various forms of disability and special needs.

Relevant legislation such as the Constitution of Kenya 2010 including the Bill of Rights, and the HIV & AIDS Prevention and Control Act 2006, should be provided to PLHIV and their communities in an easily format to understand through production and distribution of popular simplified versions.

Consideration needs to be given to make the legislation accessible in formats that facilitate the inclusion of the different categories of persons with disabilities. Community educators, once educated on these issues, should make use of creative mediums for disseminating the information including music, drama, cultural art, and dance, which are entertaining as well as informative.

Radio and TV are an effective media for disseminating information to community groups, particularly in rural areas. Radio debates and road shows on issues related to the rights of PLHIV should be carried out and their impact assessed on a regular basis.

Medical training institutions: The medical training institutions should be encouraged to prioritize HIV curriculum within their institutions, and should also be monitored as to whether they implement the same.

Policy Work

There is a need to ensure that government policy addresses these concerns and that the said policy is implemented effectively by providing effective channels through which respect of human rights can be monitored and breaches reported and dealt with without fear of reprisal through well understood mechanisms.

Since some PLHIV reported being excluded from some insurance services because of their status, there is a need to engage with the insurance industry through GOK as well as civil society channels to negotiate acceptable health terms for PLHIV that do not exclude them from healthcare on the basis that they have a pre-existing condition, and that addresses their vulnerability to opportunistic infections. In addition, there is a need for close monitoring of laws and policies to ensure that they do not create barriers to treatment and care for PLHIV and to enhance implementation to the latter.

As the country’s health sector embraces new technology including electronic records as part of the health management information systems, these findings could inform deliberate steps to ensure the right to privacy and its protection is at the centre of any proposed intervention to enhance the quality of delivery and uptake of health service by PLHIV in Kenya.

Access to Justice

There is a need for systematic monitoring of the implementation of laws and policies aimed at protecting the rights of PLHIV, and documentation of any problems in this regard through the creation and thereafter implementation of regular, documented, assessments of the understanding and knowledge capacity of communities of PLHIV of these laws.

Since some PLHIV indicated inadequate knowledge of procedures to access justice and lack of funds as a hindrance to pursuing justice, PLHIV need to be given access to legal aid through strategic partnerships with legal aid organization thus enabling them to access legal representation to bring challenges against human rights violations and discrimination cases. Advocacy for the enactment of the Legal Aid Bill, 2013 as it will obligate the government to provide aid.

As a way forward, there is need to raise the level of awareness of the PLHIV and HCW through trainings, seminars, workshops, dialogues at the national and county level, religious and social gatherings as well as the Media. There is need for increased frequent publicity through the media of human rights with emphasis on rights related to HIV. To increase the level of awareness of policy documents containing the provisions on rights to privacy and confidentiality, the documents containing easy to comprehend and disseminate provisions of rights to privacy and confidentiality should be printed and availed to the HCW, peer mentors, counselors and support groups through known and acceptable forums to further levels of awareness.

As a way of reducing or eliminating stigma, there is need for education to the civil society and the community at large on HIV and the rights of PLHIV. This calls for collaboration with HIV support groups and HCWs. Such systematic and periodical trainings and collaborative work would help reduce community and institutional based stereotypes that propagate stigma.

Gaps for future studies

There was mention in the data gathering process of several issues that constitute gaps that should be given closer scrutiny.

• The institutions that partner with the GOK in HIV work. Their opinions and thoughts were not captured neither did we seek to understand their actual role in this entire HIV/AIDS care process. The influence and impact of these institutions were also not captured and therefore not analyzed.
• The overall study did not also take into account the follow up processes to ascertain the effectiveness of previous interventions on rights to privacy and confidentiality. In the absence of this process it becomes futile to carry out new studies when the previous ones have not been comprehensively understood.
• Gender studies with a specific bias to rights to privacy and confidentiality also need to be considered. This would assist greatly in determining specific and targeted interventions.
• This being a pilot study, there is need for up scaling of such to national level in a bid to uphold privacy in all the 47 counties.
Appendix 1

SECTIONS & PERSONAL DETAILS? (Please mark the following Questions with a ✓ – tick)

1.1 What is your gender?
- Male ✓ 1
- Female ✓ 2

1.2 What is your age?
- 18 – 25 years ✓ 1
- 26 – 30 years ✓ 2
- 31 – 35 years ✓ 3
- 36 – 40 years ✓ 4
- 41 years or more ✓ 5

1.3 What is your marital status?
- Single ✓ 1
- Married ✓ 2
- Divorced ✓ 3
- Widow/widower ✓ 4
- Cohabiting ✓ 5

1.4 What is your religion?
- Christian ✓ 1
- Muslim ✓ 2
- None/no confession ✓ 3
- Do not want to disclose ✓ 4
- Other_____________ ✓ 5

1.5 Are you a person with Disability?
- Yes ✓ 1
- No ✓ 2

1.6 If yes, what is your type of disability?
- Partial/complete hearing impaired ✓ 1
- Blind/low vision ✓ 2
- Physical/mobility impairment/paraplegic ✓ 3
- Physical/mobility impairment/quadriplegic ✓ 4
- Learning difficulties ✓ 5
- Mental health impairment ✓ 6
- Multiple disabled ✓ 7
- Other ✓ 8
1.7 Where do you live?
___________________________________________

1.8 What is your level of education?

- None
- Primary school
- Secondary School
- Certificate/Diploma
- Bachelor's Degree
- Post-Graduate Degree

1.9 What is your current employment status?

- Employed
- Unemployed
- Not looking for work
- Student (full-time)
- Student (part-time)
- Volunteer

1.10 If you are employed, what type of employment?

- Semi-skilled
- Skilled
- Unskilled

1.11 If you employed, what is your designation at your place of work?

1.12 If you are employed, what is your current monthly income?

- No income
- Up to Kshs 5,000
- From Kshs 5,000 to 15,000
- From Kshs 15,000 to 25,000
- Above Kshs, 25,000

1.13 How does your work put you in contact with HIV infected individuals?

1.14 How many people at your work place have received ample training in managing HIV infected persons?

---

**SECTION B: INFORMANT’S LEVEL OF UNDERSTANDING OF HUMAN RIGHTS & THE RIGHT TO PRIVACY**

2.1 What are your main sources of information on Human Rights and the right to privacy? (Please mark the following sources with ‘√’ - tick as many as you think answers the question)

- TV
- Radio
- Friends/Peers
- Parents
- Health Workers
- Civil Society Organisations
- Peer educators/Counsellor
- Parents
- Brothers/sisters
- E-Newsletter
- Teachers/Lecturers
- Church/mosque/synagogue
- Newspapers
- Magazines
- Posters
- Video
- Street Signage
- Internet
- Other (specify)

2.2 What do you understand by the term “human rights”?

2.3 Have you heard about Chapter IV of the Kenyan Constitution that contains the Bill of Rights?

2.4 Have you read the provisions of Chapter IV of the Kenyan Constitution that contains provisions on the right to privacy?

2.5 Have you heard about the HIV & AIDS Prevention and Control Act 2006 and its provision on the right to privacy?

2.6 Have you heard about the National guidelines for HIV Testing and Counseling in Kenya (2010)?

2.7 Have you heard about the National guidelines for HIV Testing and Counseling in Kenya that touch on matters of privacy (2010)?

2.8 Have you heard of the HIV tribunal?
2.13 Do you know what the GOK policy on HIV is?

2.14 Do you know if there is a policy in HIV training curriculums at the Medical Training Centre and the medical schools at University of Nairobi, and other emerging Universities offering degrees in medicine?

2.15 If you have heard about the above Laws, policies and institution please specify where you heard about them from?

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Source of awareness</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) The Bill of rights in the Constitution and the right to Privacy</td>
<td></td>
</tr>
<tr>
<td>b) The HIV&amp; AIDS Prevention and Control Act 2006 and its provisions on the right to privacy</td>
<td></td>
</tr>
<tr>
<td>d) The HIV Tribunal</td>
<td></td>
</tr>
</tbody>
</table>

SECTION C: EXPERIENCES OF BREACH OF THE RIGHT TO PRIVACY BY THE INFORMANT

SECTION FOR HEALTHCARE WORKERS

3.1 Have you ever disclosed a person’s HIV status without their consent?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

3.2 Why were you unable to obtain their consent?

<table>
<thead>
<tr>
<th>Person was not willing</th>
<th>Person was unconscious</th>
<th>Person was below the age of 18</th>
<th>I did not know that I had to get the persons’ consent</th>
<th>Person had a mental disability</th>
</tr>
</thead>
</table>

3.3 In what circumstances should healthcare workers be allowed to disclose the HIV status of person without their consent?

<table>
<thead>
<tr>
<th>When a person gives his written consent</th>
<th>If the person is child when the guardians give consent</th>
<th>If the person has a mental disability and his legal guardian gives consent</th>
<th>If the court requires the information</th>
<th>For purposes of an epidemiological study or research</th>
<th>When it’s in the best interest of the patient</th>
</tr>
</thead>
</table>

3.4 Are there institutions or persons that require you to disclose a person’s HIV status when they receive treatment at your facility?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

3.5 Do you have privacy guidelines on storing of HIV information at your facility?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

3.6 What safeguards are in place to ensure privacy and confidentiality of health information systems including computerized medical databases and other technological advancements are in place?

3.7 How can you contribute to the development of standards, policies, and laws that protect patient privacy and the confidentiality of health records/information?

SECTION D: FOR PERSONS LIVING WITH HIV

4.1 Has your HIV status being disclosed by a healthcare worker to another person without your consent?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>I don’t know</th>
</tr>
</thead>
</table>

4.2 If yes, who was the other person that was giving information about your HIV status without your consent?

<table>
<thead>
<tr>
<th>Spouse</th>
<th>Child</th>
<th>Partner</th>
<th>Insurance Company</th>
<th>Other</th>
</tr>
</thead>
</table>

4.3 Did you report the act of your HIV status being disclosed without your consent to anyone?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

4.4 If yes, to whom did you report to?

1) _____________________________________

2) _____________________________________

3) _____________________________________

4.4 What action was taken?

__________________________________________________________________________________________

__________________________________________________________________________________________

__________________________________________________________________________________________
4.5 If no, why didn’t you report?

__________________________________________________________________________________________
________________________________________________________________________________

4.6 Are their circumstances your HIV status can be shared? If no, with whom should it be shared?

__________________________________________________________________________________________
________________________________________________________________________________

4.7 Do you think adolescents have a right to privacy of their HIV status?

Yes ☐ 1
No ☐ 2

4.8 Do you think lack of this right is restricting their access to services or the liberty of HCW in offering effective services to adolescents?

Yes ☐ 1
No ☐ 2

4.9 Have you ever faced violence or stigma as a result of your HIV status being disclosed without your consent?

Yes ☐ 1
Sometimes ☐ 2
Never ☐ 3

4.10 If yes what was the nature of the violence (Do not read options)

| Psychological violence: insults, spitting, continuous humiliation, ignoring | ☐ 1 |
| Threats or blackmail | ☐ 2 |
| Never | ☐ 3 |
| Beating, hitting with objects, kicking | ☐ 4 |
| Throwing objects on you | ☐ 5 |
| Sexual abuse (torture) | ☐ 6 |
| Sexual (physical) assault | ☐ 7 |
| Rape or an attempt for rape | ☐ 8 |
| Dispossessing / destruction / damaging of personal property | ☐ 9 |

SECTION E: SOCIO-ECONOMIC FACTORS

5.1 Do you seek to know the socio-economic backgrounds of those who seek HIV&AIDS related care?

Yes ☐ 1
No ☐ 2
I don’t know ☐ 3

5.2 If yes why do you. If not why not?

__________________________________________________________________________________________
________________________________________________________________________________

5.3 Do you think the economic status of a patient influences their care seeking behavior?

Yes ☐ 1
No ☐ 2
I don’t know ☐ 3

5.4 What do you understand by the word stigma?

__________________________________________________________________________________________
________________________________________________________________________________

5.5 What would you say is the main contributor to stigma as?

The work place ☒ 1
Within the health facilities ☒ 2
Among policy makers ☐ 3
Insurance Company ☐ 4
Within families ☐ 5

5.6 Do you know how many HIV trained counselors there are in our referral hospitals in the country?

Yes ☐ 1
No ☐ 2
I don’t know ☐ 3

5.7 How can research influence policy?

__________________________________________________________________________________________
________________________________________________________________________________

5.8 Are care givers involved in the process of policy development in HIV related issues?

Yes ☐ 1
No ☐ 2
I don’t know ☐ 3

Thank you very much for taking time to participate in this study.
FOCUS GROUP DISCUSSION GUIDE

Promoting The Rights To Privacy And Confidentiality Of HIV Positive Patiens In Health Care Settings

FGD Participant Information
The FGD will be conducted by skilled personnel one note taker and an assistant. The lead will read the following information to the participants before giving them the consent to read and sign should they consent to participate.
Before you decide to participate in this FGD, we would like to inform you that your participation in this process is voluntary. You can opt to withdraw at any point of the discussion process. There are benefits and possible risks in this process, none of which will threaten or harm your life but which you are nonetheless required to read and process as you read the consent form. You will be given a copy of the consent form for your personal reference. You are required to ask us to explain anything you do not understand or which may not be clear to you. Names will not be used at all during the FGD and the information we gather will be kept confidential and only be used for the purposes mentioned in the consent form. This study is sponsored by the International Development Research Centre and Privacy International.

Question guides.
The lead Social Scientist will ask one question at a time and allow for discussions and participation of the whole group of participants.
Participants level of understanding of terminology.
1. What do you understand by the terms Human Rights and Privacy?
2. What do you understand by the term human rights violation?
3. What are your main sources of information on Human Rights and the right to privacy?
4. Do you know what the GOK policy on HIV is?
5. Have you read or heard of the National guidelines for HIV Testing and Counseling (2010)?
6. Have you ever encountered issues surrounding the disclosure of a person’s HIV status without their consents?
7. In your view what circumstances should healthcare workers be allowed to disclose the HIV status of a person without their consent? (Probe for examples without names being disclosed)
8. Do you know if there are privacy guidelines on storing HIV information at your facility? (Probe for details of the existence of safeguards and other technical appliances set in place to ensure this, e.g. computerized health records, information systems etc.)
9. What do you understand by the term Stigma and has it affected you at all? (Probe for work place influences, socio-economic status and effect of disclosure)
10. Describe in details the policies and support available in your home area for PLWA?

For persons living with HIV

Appendix 2

NOTES
KELIN is a human rights NGO working to promote and protect HIV related human rights in Kenya. We do this by providing legal services and litigation, conducting trainings on Human rights, engaging in advocacy campaigns to influence policies that guarantee right to health and undertaking research that promotes evidence-based change.