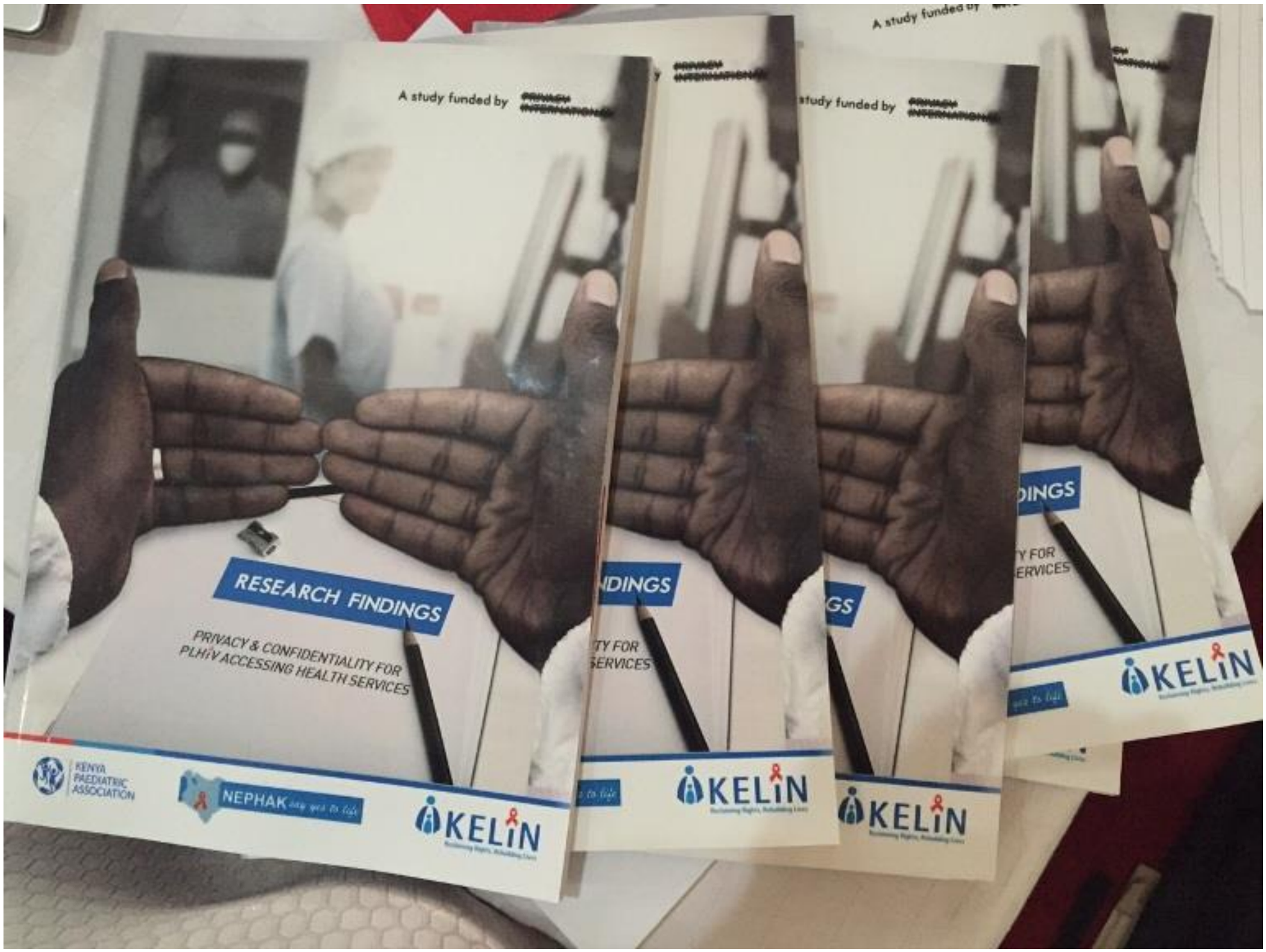
REPORT OF THE LAUNCH OF THE RESEARCH FINDINGS ON THE RIGHT TO PRIVACY AND CONFIDENTIALITY FOR PLHIV ACCESSING HEALTH SERVICES

18, December 2014



KELIN
Reclaiming Rights, Rebuilding Lives

PRIVACY
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Abbreviations and Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ICW-K	International Community of Women living with HIV- Kenya
IEC	Information, Education and Communication
HCW	Health Care Workers
HERAF	Health Rights Advocacy Forum
HIV	Human Immuno-deficiency Virus
KANCO	Kenya AIDS NGOs Consortium
KEMRI	Kenya Medical Research Institute
KMWA	Kenya Medical Women Association
KNH	Kenyatta National Hospital
KPA	Kenya Paediatric Association
NASCOP	National AIDS and STI Control Programme
NEPHAK	National Empowerment Network for PLHIV in Kenya
PLHIV	Persons Living with HIV
PMTCT	Prevention of Mother to Child Transmission
WOFAK	Women Fighting AIDS in Kenya (WOFAK)

1.0 Introduction and Background

The need to conduct a study on the right to privacy and confidentiality for People Living with HIV (PLHIV) accessing healthcare services was informed by a prior research conducted by KELIN in 2012. The research revealed that healthcare settings rank third in violation of the rights of PLHIV, after the family and work place settings. The right to privacy and confidentiality in particular was found to be one of the most violated rights for PLHIV seeking services in healthcare facilities. KELIN with the support of Privacy International therefore took forward the findings of the 2012 study by conducting a research that sought to establish the levels of awareness among health care workers (HCWs) and PLHIV of the right to privacy and the extent of violation of the right.

In 2014, KELIN collaborated with the National Empowerment Network for PLHIV in Kenya (NEPHAK) and Kenya Pediatric Association (KPA) to carry out a further study 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. 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 sought to establish the practices of health care workers within the health care setting as far as rights to privacy and confidentiality of HIV positive patients are concerned. It also aimed at establishing the level of awareness of PLHIV and HCW on their rights to privacy and confidentiality.

Following the study, a dissemination forum was convened on 18 December, 2014 at Silver Springs Hotel in Nairobi with objectives to;

- Disseminate the findings of the research on the right to privacy and confidentiality of PLHIV accessing health services;
- Receive feedback from stakeholders on taking forward recommendations from the research on upholding the right to privacy and confidentiality

2.0 Experiences on the Right to Privacy and Confidentiality in Health Care Settings

2.1 Representative of PLHIV – Maurine Murenga

Ms. Murenga noted that disclosure of HIV status would not need to be protected in an ideal situation where such disclosure would have no repercussions. Unfortunately, due to stigma and discrimination associated with HIV, the reality for most PLHIV is that disclosure of their HIV status exposes them to a host of human rights violations hence the need to protect HIV status from unlawful disclosure. Despite a constitutional and legislative framework that guarantees the right to privacy and confidentiality, she observed that certain practices in health care settings, though well-intentioned, still amount to unwarranted disclosure of HIV status of persons who visit the facilities. She gave the example of labelled rooms within health facilities such as PMTCT rooms, viral laboratories and mentor mother rooms. It is usually presumed that persons who seek services in these rooms are HIV positive. This kind of labelling has led to some PLHIV shunning the services offered in the rooms to the detriment of their health and that of their unborn children for expectant mothers.

Health commodities such as mosquito nets and condoms packaged as specifically meant for PLHIV also expose PLHIV who receive them to unwarranted disclosure of status, resulting to stigma from members of the society who spot recipients of the commodities. Ms. Murenga noted that this subtle disclosure of HIV status has been witnessed by PLHIV who often get remarks from non-medical staff like " today is not your clinic day" or "you are going to the wrong place" when they visit health facilities for different reasons. Some of the staff has gone to the extent of asking the PLHIV in public if they had told their spouses and family about their HIV status.

Another violation of the right to privacy for PLHIV accessing health services that were pointed out by Ms. Murenga was the practice of providing HIV testing and counseling services in mass. The practice is mainly carried out during antenatal clinics and it violates the right to privacy and confidentiality, as everyone knows that those normally asked to remain behind after the tests have been conducted are HIV positive. This kind of exposure, she noted, has contributed to the shunning of health care services by some PLHIV.

2.2 Representative of Health Care Workers – Charles Obange

On his part, Mr Obange shared challenges faced by health care workers with regard to upholding the right to privacy and confidentiality for PLHIV. He noted that the challenges emanate mainly from the fact that HIV and AIDS is a multi-faceted phenomenon with a psychosocial angle that complicates issues of privacy and confidentiality of HIV status. Particularly challenging for health care workers is protection of privacy of HIV status in circumstances that necessitate shared confidentiality. He pointed out that health facilities often provide integrated services which sometimes require a health care worker who knows the HIV status of a patient to divulge this information to next health worker attending to the patient in order to facilitate comprehensive treatment and care.

Health care workers also face similar dilemmas with cases of very sick patients whose status need to be divulged to family members acting as caregivers. Another challenge is presented in the disclosure of HIV status of minors to their guardians with the aim of advising the guardian on the treatment and care required by the minor. It so happens sometimes that the minors themselves do not know their HIV status and learn their status by accident.

To put the complex manifestation of issues on the right to privacy and confidentiality into perspective, Mr. Obange narrated an experience witnessed in the context of providing home-based care to a PLHIV. Since the patient did not want her husband to find out about her status, she made certain her husband was away before directing the health care worker to her house. However, just when the health care provision session with the patient had begun, the husband returned to fetch something he had forgotten and the wife, determined to keep her HIV status secret, introduced the health care provider as a visiting cousin. Mr. Obange had also encountered another case of privacy dilemma when a patient who visited him in the company of a wife and brother refused to take his HIV medication with him for fear of his wife and brother discovering his HIV status.

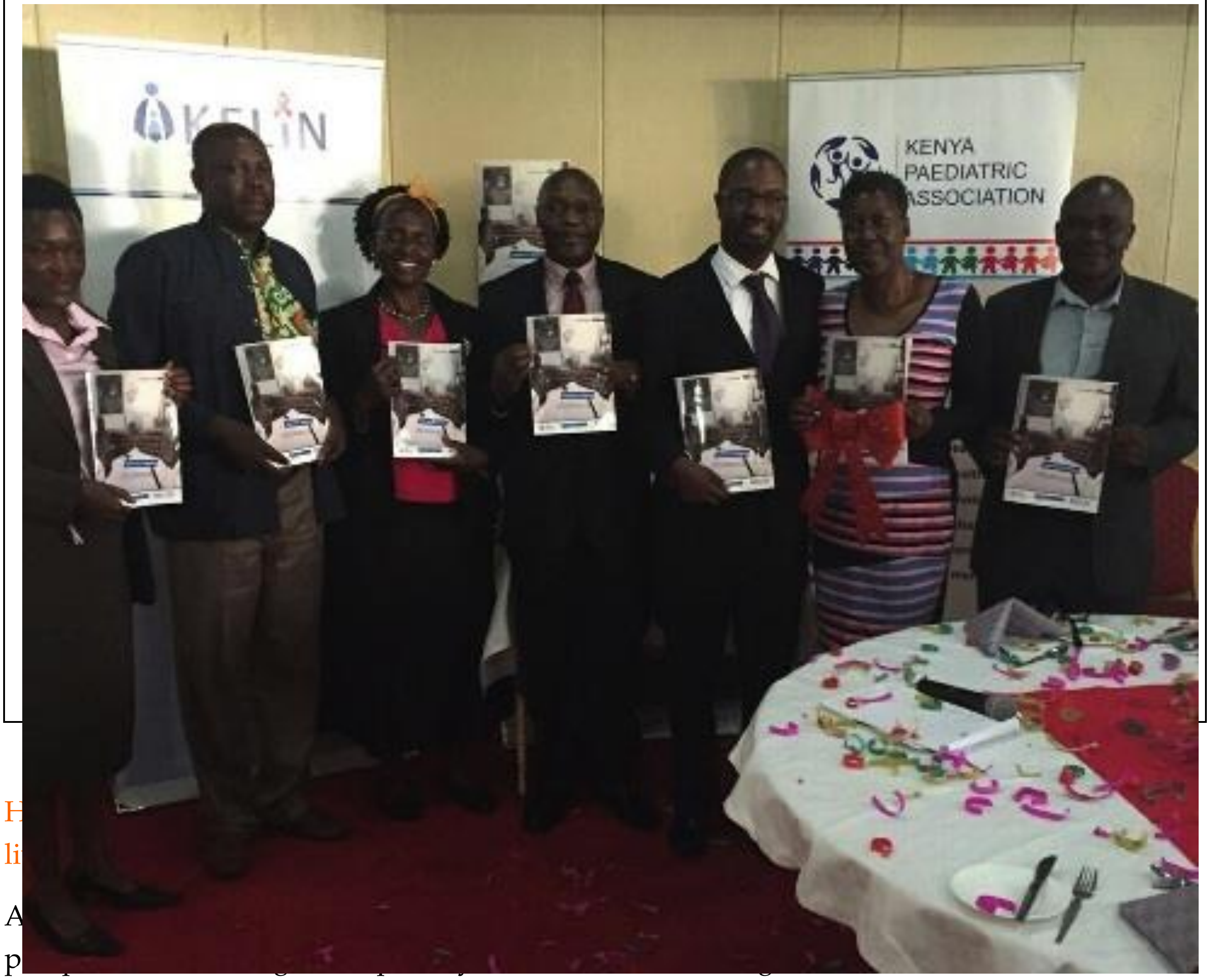
Like the speaker before him, Mr. Obange also placed violation of the right to privacy and confidentiality of HIV status at the core of cases of patients defaulting on medication and treatment. He concluded by remarking that challenges in upholding the right to privacy and confidentiality in an environment rife with stigma, discrimination and self-stigma, underlie the health care setting within which health care workers are expected to provide the best quality of service.

3.0 Official Launch of the Report and Keynote Address

The official launch of the research report was preceded by a keynote address by Mr. Ambrose Rachier. He underscored that privacy and confidentiality are at the root of all interventions needed to arrest the spread of HIV. Even so, he added that it remains the most controversial issue in HIV rights. Breach of privacy, he said, fuels stigma which in turn leads to discrimination of PLHIV. Mr. Rachier noted that the research findings on the right to privacy and confidentiality had revealed two crucial gaps:

- Inadequate knowledge on privacy as a right, among health care workers and patients;
- People whose rights are violated do not know where to go for redress

In view of the gaps above, he highlighted the need for continued sensitization of PLHIV on their rights while also sensitizing health care workers on their obligations to respect the rights of PLHIV, particularly the right to privacy and confidentiality.



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simplified information for awareness raising. This pamphlet, which KELIN has developed in English, Kiswahili and Brail, will be distributed to organizations working

with PLHIV communities to provide basic information to their partners and beneficiaries in various counties across Kenya.

4.0 Overview of the Report

4.1 The Legal and Regulatory Framework Governing Privacy and Confidentiality in Health Settings

The second chapter of the research report outlines the legal and regulatory framework governing privacy and confidentiality in health settings. This chapter seeks to create a better understanding of the right to privacy and confidentiality and the mechanisms in place to protect that right in relation to PLHIV. It also provides information on mechanisms for redress when the right to privacy and confidentiality is breached.

Mr. Allan Maleche, Executive Director of KELIN observed that laws and policies that address privacy and confidentiality have been put in place and these include the Constitution, the HIV Prevention and Control Act 2006, relevant court decisions and guidelines developed by NASCOP on testing and counseling. He also observed that the courts have been active in ensuring the protection of this right for PLHIV in Kenya.

The research conducted on privacy and confidentiality, sought to establish the level of awareness and whether the laws and policies are being implemented effectively. For effective implementation, Mr. Maleche remarked that it is vital for PLHIV and health care workers to understand the legal and regulatory framework governing privacy and confidentiality in health care settings.

The research findings revealed that 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 it is safeguarded in health care service delivery. Mr. Maleche stressed the need to enhance appreciation of the legal framework that protects the right to privacy and confidentiality and concluded by highlighting in equal measure the need for enhanced knowledge on available redress mechanisms when the right is breached.

4.2 Key Findings and Recommendations

Key findings and recommendations of the research report were highlighted by Professor Fred Were. He highlighted that the study was conducted to provide specific information about legal and policy provisions and practices in relation to privacy and confidentiality. He remarked that justification for the research was informed by the need to establish whether health care providers knew the appropriate behavior expected of them towards PLHIV and if they knew, whether they were practicing it. On the part of PLHIV, he explained that the research was an inquiry into whether PLHIV knew about protection of their rights. He noted that this detailed information could inform policies and improve the right to privacy and confidentiality in the context of the status of HIV positive patients.

Mr. Were also explained the research process involved random identification and recruitment of study participants. The study used both qualitative and quantitative approaches where a team of six research assistants administered twenty questionnaires to PLHIV, and another twenty to HCWs. Two focus group discussions (FGDs) were also conducted: one with the PLHIV and another with HCWs. 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 data was thereafter analyzed based on the study objectives. Mr. Were explained that the research was a pilot study mainly because the subject of interrogation was sensitive. He however expressed hope that the study will be provocative enough to trigger interest into larger inquiries geared at protecting the rights of PLHIV.

The main findings of the study were as follows;

- There is a general basic understanding of the concepts of human rights and of privacy as a human right among respondents. Specific knowledge is low.
- Respondents had low awareness of legal institutions and instruments that deal with human rights violations and HIV related issues.
- Breach of the right to privacy occurs in health care settings as well as in other settings such as the workplace, the family and in the insurance sector. Despite the breach, majority of PLHIV do not seek redress due to inadequate knowledge on rights and mechanisms for redress.
- Practical implementation of the right to privacy and confidentiality is poor. The measures taken by health care facilities to protect the right are only minimal.

Prof. Were elaborated that health care workers could deduce the significance of the study from the findings on inadequate knowledge on the right to privacy and confidentiality even though they took the Hippocratic Oath that protects this very right. He pointed out that the divide between knowledge and practice by healthcare providers can be bridged by studies such as this one and hoped that a post-pilot study will also be conducted to further assess the state of protection of the right to privacy and confidentiality for PLHIV.

Recommendations from the research include:

- Community education using chiefs, village elders, HIV support groups, religious leaders and community leaders with the aim of raising the level of understanding of human rights generally and the right to privacy and confidentiality in particular;
- Periodic consultative forums between PLHIV and health care workers to reinforce the obligation of confidentiality among health care workers and establish a relationship of trust in which PLHIV can securely seek health services without fear for unwarranted disclosure of their HIV status;
- Training of health care workers in order to equip them with knowledge to identify and address rights violations suffered by PLHIV in health care settings, with particular emphasis on the right to privacy and confidentiality;
- Education of potential employers through the media to pre-empt violation of the rights of PLHIV in the workplace setting;
- Alignment of current HIV guidelines and policies used by health care providers with the provisions of the HIV and AIDS Prevention and Control Act 2006;
- Enabling of PLHIV to access justice in case of violation of their rights through legal assistance;
- Channeling educational information on HIV rights through the most frequently used sources of information by PLHIV

5.0 Plenary

After sharing of the main findings and recommendations of the research report, participants attending the dissemination forum opened the floor for deliberations. Their views and observations on the research and recommendations drawn from it are captured below.

- A participant recommended massive initiatives aimed at encouraging PLHIV to disclose their status for them to receive support in the family and the workplace;
- A participant expressed concern at cases of expectant mothers who do not take precaution to protect their unborn children from HIV infection. It was noted by

fellow participants that such mothers are often driven away from preventive health services by violation of the rights of PLHIV in health care settings;

- A participant proposed training of health care workers on HIV legal issues at the college level because post-college training does not offer maximum opportunity for inculcation of a human rights based approach to health care service delivery;
- A participant proposed that data on the routine indicators of the quality of health care should be regularly collected to assess progress of health care facilities in promoting a rights based approach to health care;
- The need for creating champions of change among respected members of society living with HIV was also proposed in light of the fact that this would reduce stigma on HIV. If people recognized as role models disclosed their HIV status, perceptions associating HIV with a certain class of people would cease;
- One participant pointed out the need to relook at the quality of HIV counselling services offered by health practitioners in an effort to combat self-stigma;
- A participant questioned the gravity of the violations of PLHIV seeking health services at the grassroots levels where people are less informed if the research findings in Nairobi revealed frequent violations of the right to privacy and confidentiality.
- Participants found out that IEC materials were not the primary source of information in HIV rights as they had previously thought. They felt that there is therefore need to invest in sources of information that reach a wider audience.
- The session was concluded by story of a woman living with HIV who had faced stigma after giving birth. She indicated that she had been advised not to breastfeed her baby and the inference that her neighbours drew from her lack of breastfeeding was that she was HIV positive. Word on her HIV status went around until she had to move houses due to the stigma neighbours meted on her. Her husband abandoned her as a result of stigma and for the same reason; she can no longer visit her in-laws.

6.0 Remarks on Behalf of the National AIDS Control Council

Ms. Fridah Mwende made remarks on behalf of the National AIDS Control Council. She commended KELIN for carrying out the study on the right to privacy and confidentiality for PLHIV accessing health services and added that the study was timely as it follows the recent launching of the National Strategic Plan Framework on HIV. She urged stakeholders to harness efforts towards addressing the gaps revealed by the study. Ms. Mwende concluded by noting that the National AIDS Control Council was in the process of developing a HIV research agenda. She promised that the findings and recommendations of the study on the right to privacy and confidentiality for PLHIV would be incorporated in the agenda. Finally, she asked participants to not only disseminate the research report but to also implement the findings and recommendations.

7.0 Closing Remarks

Mr. Nelson Otwoma of NEPHAK made the closing remarks on behalf of stakeholders in the HIV sector. He expressed regret at the long period of time it took for the study on the right to privacy and confidentiality to receive approval. Mr. Otwoma felt that the study recommendations on community education were critical and underscored that education on HIV and epidemiology of the virus should precede human rights education for maximum impact on reduction of stigma and discrimination. This, he noted, was in light of the fact that so many people mete out HIV related stigma and discrimination out of ignorance. He concluded by urging wide dissemination of the research findings after which he declared the dissemination forum closed.

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8.0 Appendices

Appendix 1: Programme

THE LAUNCH OF THE RESEARCH FINDINGS ON THE RIGHT TO PRIVACY AND CONFIDENTIALITY FOR PLHIV ACCESSING HEALTH SERVICES

18 December, 2014

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TIME (AM)	SESSION	FACILITATOR
0700 - 0710	Arrivals and Registrations	
0710 – 0720	Introductions	Overall Moderator
0720 - 0730	Background of Project	Melba Katindi KELIN
0730 – 0740	Experiences on the right to Privacy and Confidentiality in health settings	Representative PLHIV Representative HCWs
0740 - 0800	**Official Launch of Report and Key Note Address**	**Mr. Ambrose Rachier** **Chairperson, KELIN** **Chairperson, KEMRI-ERC** **Immediate Former Chairperson, Equity (HIV & AIDS) Tribunal**
0800 – 0830	Overview of the Report	
	The Legal and Regulatory framework governing Privacy and Confidentiality for PLHIV in Kenya	Allan Maleche Chairperson, KELIN
	Key Findings and Recommendations	Prof. Fred Were KPA
0830 - 0900	**Reactions to Findings and Recommendations**	
	Remarks on behalf of People Living With HIV in Kenya	Nelson Otwoma NEPHAK
	Remarks from Management, Kenyatta National Hospital	Representative KNH
	Remarks from the NACC	Representative NACC

	Remarks from County representative on Health – Nairobi County	Representative County Director of Health Nairobi County
	Remarks from research expert	Elizabeth Bukusi KEMRI-ERC
0900 – 0925	**Plenary**	
0925 - 0930	Vote of Thanks	Melba Katindi KELIN
0930 – 10.00	**Breakfast and Departure of Guests**	

Appendix 2: List of Participants

No.	Name	Designation	Institution
1	Allan Maleche	Executive Director, Lawyer	KELIN
2	Ambrose Rachier	Chairperson, Lawyer	KEMRI-ERC & KELIN
3	Ann Muriithi	Client	KNH
4	Beatrice Gachambi	Program Officer	HERAF
5	Charles Obange	Counselor (HCW)	KNH
6	Danson Warui	Program Manager, Paediatrics (HCW)	Coptic Hospital
7	David Githango	Chairperson, Paediatrician	KPA
8	Dorothy Onyango	Executive Director	WOFAK
9	Edgar Makona	M&E Officer	KELIN
10	Elizabeth Bukusi	Professor, Chief Research Officer and the Deputy Director (Research and Training)	KEMRI
11	Fred Were	Paediatrician	UoN/ KPA
12	Fridah M. Muinde	M&E Officer	NACC
13	Hilda Ojiambo	Lawyer	Rapporteur Consultant
14	Inviolata Mmbavi	Coordinator	ICW-K
15	Irene Amadi	Program Manager (HCW)	KPA
16	Jackson Agufawa	Executive Director	Kenya Union of the Blind
17	Joyce Matogo	Manager	KANCO
18	Keziah K’oduol	Doctor (HCW)	KPA
19	Lucy Ng’ang’a	Nurse (HCW)	Mbagathi Hospital
20	Margaret Lumumba	Nurse (HCW)	Mbagathi Hospital
21	Maurine Murenga	Representative (WLHIV)	Lean on Me
22	Melba Katindi	Program Officer, Lawyer	KELIN
23	Nelly Opiyo	Psychologist (HCW)	KNH
24	Nelson Otwoma	Executive Director	NEPHAK
25	Pamela Njuguna	Doctor/ Public Health Specialist, Chairperson	KMWA
26	Patrick Kang’ethe	Program Assistant, Lawyer	KELIN

27	Patrick Maina	Client	KNH
28	Regina Mwanza	Communications Officer	KELIN