



A PILOT STUDY TO EVALUATE THE EXPERIENCES OF TB PATIENTS WHEN  
ACCESSING TB SERVICES IN FIVE HEALTH FACILITIES IN KISUMU COUNTY

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# List of acronyms, abbreviations/ Glossary

**KELIN**- Kenya Legal and Ethical Issues Network on HIV & AIDS

**KEMRI**- Kenya Medical Research Institute

**TB**- Tuberculosis

**ERC**- Ethics Review Committee

**FGD**- Focus Group Discussions

**HIV**- Human Immunodeficiency Virus

**HBC**- High Burden Countries

**MDR-TB**- Multi drug resistant tuberculosis

**USD**- United States Dollar

**CG** - Care givers

**CHW**-Community Health Workers

**UDRH**- Universal Declaration of Human Rights

**WHO**- World Health Organisation

**XDR-TB**- Extensively drug resistant tuberculosis

**DS-TB**- Drug susceptible tuberculosis

**DR-TB** – Drug resistant tuberculosis

**GOK** – Government of Kenya

## Acknowledgments

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 the participants and the sharing of their experiences provided invaluable information for people working in TB prevention and management to address the shortfalls in TB service delivery.

I would like to appreciate the Principal Investigators Allan Maleche, Belice Odamna & Khairunisa Suleiman, Co-investigators; Maureen Murenga & Joseph Odhiambo for their untiring efforts in ensuring that the study met its intended objectives. Special appreciation goes to the research team for their excellent support: Mr. Edgar Makona led the team in data collection and analysis of the study results; Ms. Murenga was instrumental in recruitment and mobilization of the study participants. The legal analysis was written by Ms. Belice Odamna. The final report was edited by Ms. Lucy Ghati, Ms. Matsha Carpentier & Impact Africa. 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, including Kenya Medical Research Institute (KEMRI) Ethical Review Committee who approved the proposal for the study and Lean on Me Foundation who identified the research assistants and research participants. 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 TB management, control and prevention.

Lastly I wish to thank the management of Jaramogi Oginga Odinga Teaching and Referral Hospital, Kisumu District Hospital, Lumumba Health Centre, Kombewa District Hospital & Nyando District Hospital for allowing us to use their facilities. And to the Stop TB Partnership, thank you for funding the study.

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## Executive Summary

This pilot study was carried out by KELIN, seeking to evaluate the perceptions of patients, health care workers and members of the community on TB prevention and management and to document the health service experiences of patients with suspected TB during the course of their treatment.

Research has been identified as a critical component of TB care and control, and particularly on social cultural determinants of the disease and ways to prevent the diseases; effectiveness of infection control measures, adherence strategies, drug delivery mechanisms and non-bio-medical interventions (social, behavioural, etc); social, cultural and anthropological studies about individuals' and communities' understanding of the disease. Therefore an assessment on TB health services provided to patients with suspected TB and perceptions of community members on TB management will greatly contribute to intervention strategies on improving TB prevention and care within the county. These intervention strategies are potentially replicable across the country.

This research was conducted at Jaramogi Oginga Odinga Teaching and Referral Hospital, Kisumu District Hospital, Lumumba Health Centre, Kombewa District Hospital & Nyando District Hospital, after receiving approval from the KEMRI/ Scientific and Ethics Review Unit (ERC) for implementation effective 15 April, 2015. The process involved random identification and recruitment of study participants: patients with suspected TB (current and former) were recruited by Lean on Me Foundation while community members were drawn from the communities where these patients reside. The medical practitioners and health care workers involved in the care of TB patients were recruited by the office of the Chief Officer of Health in Kisumu County. There was one in-depth interview with the Kisumu County TB and Leprosy Coordinator. The qualitative data was analyzed descriptively while the FGDs were analyzed thematically, based on the study objectives.

## The Key Findings are:

- There is a very basic understanding of the concepts of human rights; the rights based approach in TB service delivery and rights of patients with suspected TB. The knowledge varies based on the participants' level of education, profession and role or predisposition to interact with the rights of patients with suspected TB. There is a correlation between the level of understanding of human rights and the level of education of study participants.
- Although the Constitution of Kenya 2010 and laws of Kenya provide for the protection of rights of patients with suspected TB, there is poor practical implementation and minimal measures to uphold and ensure patients' rights and the right to health, especially in health service delivery.
- The attitudes of health care workers towards patients, and the distance to health care facilities, determine whether patients will go back to hospital to receive their TB medication after their diagnosis.

According to the Kenya Ministry of Health through the National Tuberculosis, Leprosy and Lung disease unit, in 2013<sup>1</sup>, it was observed that TB remains a major global health problem. It ranks as the second leading cause of death from an infectious disease, after the human immunodeficiency virus (HIV). Globally, an estimated 8.6 million people developed TB in 2013. Nearly 80% of the global burden of TB is found in 22 countries including nine countries in Sub-Saharan Africa belong to the 22 high burden countries (HBCs). In 2013, Africa contributed 12.7% of the world population, 24.5% of TB deaths and 78.1% of HIV-positive TB related deaths. Kenya is ranked 10<sup>th</sup> among the 22 high TB burden countries. In 2012, Kenya reported about 99,159 TB cases, which was estimated to be about 76% of all TB cases that had occurred in the country. 7, 700 people were dually infected with TB and HIV.

In the year 2013 in Kenya, there was a significant decrease in reported TB cases to a total number of 89,760, a 9.48% decline from the 99,159 cases observed in 2012. There was a general decline in all TB categories with a total of 8,477 retreatment cases and 81,283 new cases being reported. There has been a worrying trend of an increase in the number of people infected with multi-drug resistant (MDR). Of the 291 cases that were reported, 254 were MDR. The TB/HIV co-infection rate was 25% among the MDR patients in 2013.

Studies<sup>2</sup> on the economic burden document between three and four months work time lost annually due to Tuberculosis, and lost earnings of 20 to 30% of household income. Families of persons who die from TB lose about 15 years of income. Malnutrition, overcrowding, poor air circulation and sanitation –all factors associated with poverty - increase both the probability of becoming infected and developing TB. Together, poverty and TB form a vicious cycle: poor people go hungry and live in close, unventilated quarters where TB flourishes. TB decreases people's capacity to work, and increases out of pocket expenditure due to treatment and transportation, which exacerbates people's poverty. Given 8.6 million

1. Kenya NTLD Unit Annual Report (2013), Nairobi, Ministry of Health, Republic of Kenya.

2. [http://www.who.int/trade/distance\\_learning/spgh/spgh3/en/index6.html](http://www.who.int/trade/distance_learning/spgh/spgh3/en/index6.html) accessed on 5 June 2014 at 2:15 pm.



were infected by TB globally in 2013 and assuming a 30% decline in average productivity, the toll amounts to approximately USD 1 billion lost yearly. According to the World Health Organisation, the economic burden of TB, translates to two million annual deaths, with an average loss of 15 years income, and an additional deficit of USD 11 billion.

Thus, approximately USD 12 billion annually is lost from the global economy due to TB. Using the same parameters approximately USD 110 million per year is lost from the Kenyan economy due to TB. The objective of this study was to assess the access to health care services for TB patients, and document their perceptions and experiences and those of members of community and health care workers in TB management.

## 1.1 Research Objectives

The general objective of the research was to conduct an evaluation of the perceptions of patients, health care workers and members of the community on TB prevention and management and to document the health service experiences that patients with suspected TB encounter during the course of their treatment.

### 1.1.1 Specific Objectives

1. To establish knowledge of TB prevention and management among patients, health care workers and community members
2. To evaluate the perceptions and experiences of patients with suspected TB, health care workers and communities on TB health service delivery and satisfaction.
3. To evaluate the incidences of the breach of the rights of patients with suspected TB in Kisumu County.

## 1.2 Methodology

### 1.2.1 Research Site

The study was conducted in Kisumu County (see Figure 1, below), in the sub counties of Seme, Kisumu East and Kisumu Central. These sub-counties are characterized with a high HIV prevalence, leading to the high TB and HIV co-infection rates.



Figure 1: A map of Kisumu County. Source: Google

### 1.2.2 Research Design and Data Collection Methods

The study adopted a cross sectional descriptive design involving both quantitative and qualitative methods. Three groups of respondents were interviewed namely health care providers, patients with suspected TB (both current and former) and caregivers of TB patients. There were questionnaires for:

- Patients with suspected TB and recovered TB patients
- Health Care Workers (nurses/clinical officers/ doctors)
- Caregivers; and An interview guide for the Kisumu County TB and Leprosy Coordinator

Five health facilities were selected for the study and five research assistants were trained for one day on the study tools and how to use them. One research assistant was assigned to each health facility for data collection. The facilities were selected because they provide both HIV & TB services to the population and receive a high number of patients. The research assistants collected data for five successive days. Three research supervisors were also deployed to carry out quality checks as the study progressed.

This research study also involved a desk review of existing literature on laws and policies that exist in relation to TB treatment, control and management in Kenya.

### 1.2.3 Sampling size and procedure

KELIN reached out to the medical superintendents of the various health facilities and informed them of the research and the need for respondent volunteers from the target group i.e. people affected by TB and health care workers. The people affected by TB who had visited the health facilities on the dates of the study were recruited for the study on a voluntary basis after discussing the study objectives. They were recruited for interviews on a 'first come first served basis' for as long as the patient agreed to be interviewed. The patients were then followed to their homes to interview their caregivers and family members.

The study used purposive sampling to select 11 health care workers who directly handle TB patients. The health care workers were recruited into the study through Lean on Me Foundation<sup>3</sup> and the office of the Chief Medical Officer of Health – Kisumu County.

We interviewed five nurses/clinicians; five community health workers and the head of TB/Leprosy and Lung health services in Kisumu County. As indicated in Table 1.1, we interviewed 27 care givers and community members (CG), held 5 in-depth interviews with community health workers (CHW), 5 in-depth interviews with health care workers (nurses/clinicians) and one interview with the Head of TB, Leprosy and Lung health services, Kisumu County.

Sub County	Health Facility	Patient Interviews	Care Giver Interviews	CHW/ CHN	Nurse/ Clinician	Head of TB, Leprosy and Lung health services
Seme	Kombewa Sub County Hospital	5	5	1	1	1
Kisumu East	Jaramogi Oginga Odinga Teaching and Referral Hospital (JOTRH)	5	5	1	1	
	Lumumba Health Centre	5	5	1	1	
Kisumu Central	Kisumu County Hospital	5	6	1	1	
Nyando	Ahero Sub County Hospital	5	6	1	1	
<b>Total</b>		<b>25</b>	<b>27</b>	<b>5</b>	<b>5</b>	<b>1</b>

Table 1.1: List of health facilities and number of interviews done

### 1.2.4 Data analysis and presentation

The qualitative data collected was transcribed and analyzed thematically. A 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 analyzed descriptively using SPSS. Qualitative and quantitative data was triangulated to build on the objectives of the study.

## 1.3 Ethical Issues

Prior to the study, KELIN sought for and received ethical approval from the Kenya Medical Research Institute (KEMRI) Ethics Review Committee (ERC) and the Kisumu County Health Office. Before the data was collected, the respondents' informed consent was obtained. The respondents were informed of the objectives, benefits and risks of participating in the study as well as of the strategies in place to uphold their right to privacy and confidentiality. The respondents appended their signatures to the consent form to show their voluntary consent.

<sup>3</sup>Lean on Me is a registered NGO which was founded to increase access to education, health and human rights for women and girls through advocacy and service provision to enable them live more meaningful lives. <http://www.leanonmekenya.org/>

# 2.0

## LEGAL AND REGULATORY FRAMEWORK GOVERNING TUBERCULOSIS PREVENTION AND MANAGEMENT

### 2.1 Human Rights

According to the Office of the High Commissioner for Human Rights (OHCHR), Human rights are rights inherent to all human beings, whatever their nationality, place of residence, sex, national or ethnic origin, colour, religion, language or any other status. These rights are interrelated, interdependent and indivisible. In the over 50 years since the adoption of the Charter of the United Nations, specificity has been given to the term “human rights” by the adoption of the Universal Declaration of Human Rights (UDHR) and numerous treaties, conventions, declarations, resolutions, guidelines, and recommendations. Governmental obligations with regard to human rights fall under the broad principles of *respect, protect, and fulfil*<sup>4</sup>.

Therefore, human rights are universal legal guarantees protecting individuals and groups against actions by governments and other third parties, which interfere with fundamental rights and freedoms of individuals. In the context of TB, this is relevant because it can bring new criteria to assessing the effectiveness of existing TB interventions and programmes in reaching the most vulnerable populations. Creating widespread awareness about government obligations can also be a means to mobilize increased resources. It also provides a framework for governments to document their own progress towards realizing their commitments.<sup>5</sup>

By virtue of Article 2 (6) of the Constitution of Kenya, international instruments that Kenya has ratified form part of the Laws of Kenya. Article 2(6) requires that we take into account international standards

4. The Universal Declaration of Human Rights is generally agreed to be the foundation of international human rights law. Adopted in 1948, the UDHR has inspired a rich body of legally binding international human rights treaties. It continues to be an inspiration to us all whether in addressing injustices, in times of conflicts, in societies suffering repression, and in our efforts towards achieving universal enjoyment of human rights. It represents the universal recognition that basic rights and fundamental freedoms are inherent to all human beings, inalienable and equally applicable to everyone, and that every one of us is born free and equal in dignity and rights. Whatever our nationality, place of residence, gender, national or ethnic origin, colour, religion, language, or any other status, the international community on December 10, 1948 made a commitment to upholding dignity and justice for all of us. <http://www.un.org/en/documents/udhr/index.shtml>

5. Stop TB Partnership, Tuberculosis and Human Rights Information Note, Geneva, 2010

and obligations in the prevention and management of TB. It provides a legal basis for holding the government accountable on international commitments relating to issues of prevention and management of TB. The key international instruments that Kenya has ratified relating to TB management treatment and control include: Article 12<sup>6</sup> of the International Covenant on Economic Social and Cultural Rights and Article 16<sup>7</sup> of the African Charter on Human and Peoples’ Rights. In addition, although not legally binding, the government must have regard for several international declarations and commitments and resolutions including the Universal Declaration on Human Rights of 1945, to which Kenya is a signatory

### 2.2 Understanding the rights of patients with suspected TB

Some of the factors that increase a person’s vulnerability to tuberculosis (TB) or that reduces their access to services to prevent, diagnose and treat TB are associated with their ability to realize their human rights. TB is deeply rooted in poverty: low socioeconomic status as well as legal, structural and social barriers prevents universal access to quality TB prevention, diagnosis, treatment and care.

Access to TB prevention, treatment, support and care services, as well as to basic necessities such as food, housing and social services, are fundamental human rights embedded in the right to health. A human rights-based approach to TB prevention, treatment and care can help overcome the legal, structural and social barriers to quality TB prevention, diagnosis, treatment and care services.

The promotion and realization of human rights is essential to overcome these barriers, and diminish peoples’ vulnerability to TB. It is also an effective response to the disease that contributes to the achievement of the millennium development goals and increases impact on health, development and human rights.

6. Article 12 of the International Covenant on Economic, Social and Cultural Rights provides:

1. The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

2. The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for:

- (a) The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child;
- (b) The improvement of all aspects of environmental and industrial hygiene;
- (c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases;
- (d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness.

7. Article 16 of the African Charter on Peoples’ and Human Rights provides:

Every individual shall have the right to enjoy the best attainable state of physical and mental health.

State Parties to the present Charter shall take the necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick.

## 2.3 Why human rights are important in TB prevention and management

According to the World Health Organisation (WHO) and Stop TB Partnership<sup>8</sup>, the integration of a human rights-based approach into TB programmes, policies and interventions can help achieve universal access to TB prevention, care and treatment through:

### 2.3.1 Contributing to TB prevention

Economic, social and cultural rights are strongly interlinked. For example vulnerability to TB infection and disease increases with a lack of access to education; appropriate nutrition; quality housing and sanitation; health services and facilities; employment and social security. Being ill with TB also increases vulnerability to poverty. A human rights-based approach addresses the socio-economic determinants of health that impact TB by ensuring that the rights to food, education, housing and social security of vulnerable and marginalized groups are promoted and protected.

### 2.3.2 Facilitating access to care:

Effective diagnosis is often hindered by cost, lack of social security or health services and other barriers associated with seeking care, such as stigma and discrimination, or lack of information and specific public policies. Accessing care can lead to catastrophic expenditures which may contribute to impoverishment for the individual and his or her entire family. These barriers can be removed if human rights implications of TB policy, legislation and programming are addressed within an integrated and multi-sector response to TB.

### 2.3.3 Empowering patients and communities:

Patients and communities play an integral role in TB treatment literacy, social support, advocacy, communication and social mobilization. TB cannot be adequately addressed without meaningfully involving representatives of the most affected communities in the designing, planning, implementation and monitoring of policies and programs that impact on them. A human rights based approach to TB places affected persons and communities at the centre, as equal partners, driving health policy, providing them with the tools to participate and claim specific rights.

8. WHO Stop TB Strategy <http://www.who.int/tb/strategy/en/>

In 2006, WHO developed a six point Stop TB Strategy which builds on the successes of DOTS while also explicitly addressing the key challenges facing TB. Its goal is to dramatically reduce the global burden of tuberculosis by 2015 by ensuring all TB patients, including for example, those co-infected with HIV and those with drug-resistant TB, benefit from universal access to high-quality diagnosis and patient-centered treatment.

### 2.3.4 Reaching key vulnerable groups:

A rights-based approach to TB requires particular attention to ensuring that the specific needs and rights of vulnerable groups are recognized and adequately addressed. Stigma and discrimination against people with TB and those vulnerable to TB can prevent those most in need from accessing TB prevention, treatment and care services.

### 2.3.5 Improving quality of services:

Poor quality of care hampers TB prevention and management efforts. Inadequate training and supervision of health workers, inconsistent drug supplies, inadequate diagnostic tests and limited resources inhibit early detection and proper management and treatment, resulting in increased transmission and poor health outcomes. By tailoring services to meet the needs of patients and communities, a human rights based approach will improve service delivery, ensure that resource use matches community priorities, and provide evidence that can be used to mobilize additional resources.

### 2.3.6 Addressing co-morbidities, including HIV:

Early diagnosis among people living with HIV is challenging but vital. Prevention, diagnosis and treatment of TB should be integrated or coordinated to meet the needs of patients with HIV, Hepatitis C, diabetes, those on opiate substitution therapy and other common co-morbidities. Integrating and coordinating services facilitates adherence and ensures patients are not forced to choose between the therapies they need.

### 2.3.7 Preventing drug resistant TB and promoting rights-respecting treatment:

Drug-resistant TB, including multi-drug resistant and extensively drug resistant TB, is associated with poor prescribing, irregular drug supply, inadequate access to quality care, mandatory treatment or confinement and inability to complete treatment. Human rights approaches emphasize appropriate treatments that meet patients' needs to prevent the development of drug resistance, patients' right to be free from discrimination (including in health care settings) and to be free from forced or coerced treatment.



## 2.4 The Constitution of Kenya

The Constitution of Kenya contains express provisions which ensure the promotion and protection of the rights of TB patients. The provisions include those on: the right to life (Article 26), equality and freedom from discrimination (Article 27), human dignity (Article 28), freedom and security of the person (Article 29), access to information (Article 35[1] [(b), Economic and social rights (Article 43), which includes the right to the highest attainable standard of health and the right to health care services and consumer rights (Article 46).

## 2.5 The Public Health Act (Cap 242 Laws of Kenya)

This is an act of parliament that makes provisions for securing and maintaining health. The act has been in force since 6th September, 1921 and has undergone numerous amendments since it came into force.

### Section 27 of the act provides:

*Where, in the opinion of the medical officer of health, any person has recently been exposed to the infection, and may be in the incubation stage, of any notifiable infectious disease and is not accommodated in such manner as adequately to guard against the spread of the disease, such person may, on a certificate signed by the medical officer of health, be removed, by order of a magistrate and at the cost of the local authority of the district where such person is found, to a place of isolation and there detained until, in the opinion of the medical officer of health, he is free from infection or able to be discharged without danger to the public health, or until the magistrate cancels the order.*

### Section 28 of the act provides:

Any person who—

*(a) while suffering from any infectious disease, willfully exposes himself without proper precautions against spreading the said disease in any street, public place, shop, inn or public conveyance, or enters any public conveyance without previously notifying the owner, conductor or driver thereof that he is so suffering; or*

*(b) being in charge of any person so suffering, so exposes such sufferer; or*

*(c) gives, lends, sells, transmits or exposes, without previous disinfection, any bedding, clothing, rags or other things which have been exposed to infection from any such disease, shall be guilty of an offence and liable to a fine not exceeding thirty thousand shillings or to imprisonment for a term not exceeding three years or to both; and a person who, while suffering from any such disease, enters any public conveyance without previously notifying the owner or driver that*

*he is so suffering shall in addition be ordered by the court to pay such owner and driver the amount of any loss and expenses they may incur in carrying into effect the provisions of this Act with respect to disinfection of the conveyance:*

*Provided that no proceedings under this section shall be taken against persons transmitting with proper precautions any bedding, clothing, rags or other things for the purpose of having the same disinfected.*

Section 27 of the Public Health Act gives the public health officer the authority to remove and request for the isolation of persons who have been exposed to infection or may be in the incubation stage of an infectious disease while section 28 provides for the penalty for exposure to infectious substance.

According to court documents and media reports, the two sections have in the past been used to unconstitutionally incarcerate TB patients for “failure to adhere” to TB treatment. The patients are arraigned in court and convicted for up to seven or eight months, or until the satisfactory completion of their TB treatment.<sup>9</sup> The manner and conditions of the incarceration endangers the patients and prison population health. In any event, the prison conditions are ideal for the rapid transmission of TB, thereby placing the public, including the prisoners, at extremely high risk of infection. Further, the Kenyan prisons do not have isolation or medical facilities where proper care and treatment of TB patients can be done.<sup>10</sup>

According to the TB Human Rights Task Force which was established by the Stop TB Partnership in a working document<sup>11</sup> on TB and Human Rights, TB is a leading killer among people living with HIV, accounting for 26% of HIV associated deaths worldwide. They further document that the leading cause of death amongst prisoners across the world is TB and that poor prison conditions including overcrowding, poor ventilation, hygiene and poor nutrition fuel TB transmission and reactivation. Based on the above it is evident that prison would not be the ideal place to isolate people affected by TB for treatment purposes.

In responding to TB from a human rights perspective, KELIN has secured the release of TB patients from prison. The High Court sitting in Eldoret in *Petition No. 3 of 2010 Daniel Ng'etich & Another v The Attorney General & Others (Unreported)*<sup>12</sup> while giving an order for the release of the petitioners, observed that the action to have them imprisoned was

9. AWW, Programme Assistant- Patrick Kang'ethe, Evidence Gathering Interview, King'ong'o GK Prison, Nyeri, May 2014.

10. PGM & EW, Programme Assistant- Patrick Kang'ethe, Evidence Gathering Interview, Kiambu GK Prison, Kiambu, May 2014

11. See, among others, TB Human Rights Task Force “Working Document on TB and Human Rights” available at <http://www.stoptb.org/global/hrtf/> accessed on 4th April, 2014

12. Ruling can be accessed at <http://kelinkenya.org/wp-content/uploads/2010/10/Ruling-on-Petition-No.-3-of-2010.pdf> last accessed on 8th May, 2014.

unconstitutional and not in compliance with the Public Health Act that it was purportedly grounded on. Similarly, in the High Court sitting in Embu in *Miscellaneous Criminal Application No. 24 of 2011 Simon Maregwa Githiru v Republic (unreported)*<sup>13</sup>, the applicant was convicted for willfully exposing and spreading infectious disease (tuberculosis) contrary to section 28 of the Public Health Act. The Court in ordering the release of the applicant wondered why the lower court did not empathize with the applicant who was a TB patient and considered the wide range of non-custodial sentences like community service or fines as provided in law.

## 2.6 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 all patients should have access to health care, the highest attainable standard of health services and the right to information, among others.

## 2.7 Tuberculosis treatment and management guidelines

### 2.7.1 Guidelines for management of Tuberculosis and Leprosy in Kenya (2013)

This guideline developed by the Department of Leprosy, Tuberculosis & Lung Disease is a revision of the earlier versions produced in 1994, 2000, 2003, 2008 and 2009. The guideline makes provision for TB management, control and prevention. The guideline gives specific provisions on TB in adults and children and TB & HIV co-infection management. The guidelines provide direction on management of drug resistant TB.

### 2.7.2 National Strategic Plan for Tuberculosis, leprosy and lung health (2015 -2018)

The Ministry of Health through the National Tuberculosis, leprosy and lung diseases program in coming up with the strategic plan, looked at the epidemiological analysis of the burden of TB and other lung diseases. The plan promotes strategic interventions that are unique for each county. For the first time, priority interventions related to key affected populations, gender and human rights are covered.

### 2.7.3 World Health Organisation: Guidance on ethics of tuberculosis prevention, care and control (2010)

The World Health Organisation undertook an analysis of selected priority ethical issues in TB. The guidance developed thereafter is for all stakeholders providing TB services on the obligation to provide access to TB services, supporting adherence to TB treatment, involuntary isolation and detention as a last resort measures, and on research on TB prevention and management.

13. Ruling can be accessed at <http://kelinkkenya.org/wp-content/uploads/2010/10/Misc-Criminal-App-No.-24-of-20111.pdf> last accessed on 8th May, 2014.

## 3.1 DEMOGRAPHY OF THE RESPONDENTS

### 3.1.1 Gender of the Respondents

Of the TB patients interviewed, 40% were male and 60% female as shown in figure 3.1.1 below. The majority (70%) of the care givers were female, while 30% were male. 80% of the Health Care Workers (HCW) interviewed were female. These figures suggest that there were more female patients, care givers and health care providers (15, 19 and 8 respectively) as compared to the male patients, caregivers and health care providers.

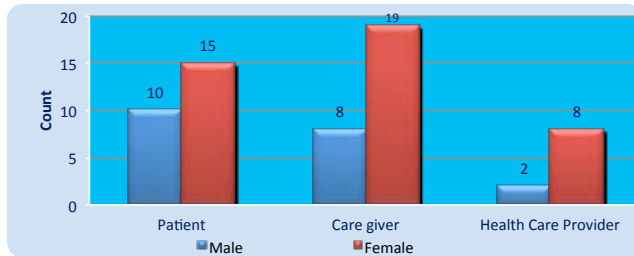


Figure 3.1.1: Gender of respondents.

### 3.1.2 Age of the Respondents

Majority of the respondents, (58%) were aged 41 years and above, as shown in Figure 3.1.2 below. TB patients aged between 18 and 25 years amounted to 12% of the respondents.

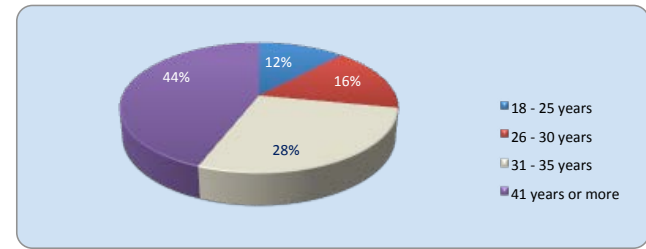


Figure 3.1.2: Ages of respondents

### 3.1.3 Marital status

From the study, 64% of the respondents were married, 20% were single, 12% were widowed and 4% were separated.

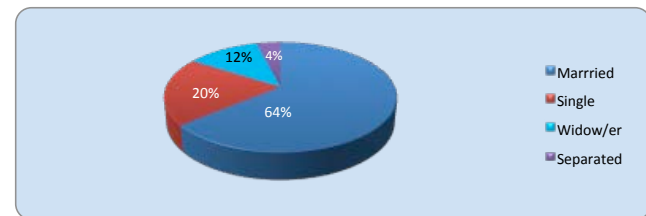


Figure 3.1.3: Marital status of patients

### 3.1.4 Level of Education

Figure 3.1.4 shows that a total of 52% of the TB patients had only primary school education, 32% had secondary school education and 12% had above secondary school education.

Education has been identified as an important social impact on health.<sup>14</sup> The patients, in their responses indicated that they did not know and understand information about TB, its prevention and management because they could not read or write. According to Feinstein, L & Others, a patient, whose level of education is high, would easily understand the dynamics of the disease and the importance of ensuring that they follow through with the Tb phase.

14. Feinstein L, & Others, What are the effects of education on health?: Measuring the effects of education on health and civic engagement- Proceedings of the Copenhagen Symposium, OECD (2006)

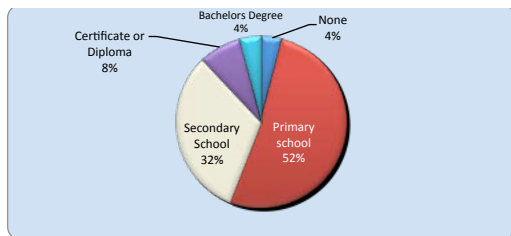


Figure 3.1.4: Highest level of education attained

### 3.1.5 Employment status and type

Among the tb respondents, one person (4%) was a government employee, two (8%) were engaged in casual work, four (16%) were employed in private businesses and eight (32%) ran their own businesses. On the other hand, 12 (44.4%) of the care givers run their own businesses and 7 (25.9%) are involved in small scale farming which means that their income is not guaranteed and depends on either the success of their business or the weather patterns. Employment or lack of employment is a key determinant of health care. Unemployment is often associated with socioeconomic deprivation and lack of access to basic health care services.<sup>15</sup>

The average income chart in Figure 3.1.5 showed that 40% of the patients had no regular income because they did not have opportunity for meaningful engagement; 28% had income of up to Kshs. 6,000 per month; 16% had income ranging from Kshs. 6,001 to 15,000 per month; 8% had income ranging from Kshs. 15,001 to 25,000 per month; another 8% had income above Kshs. 25,000 per month.

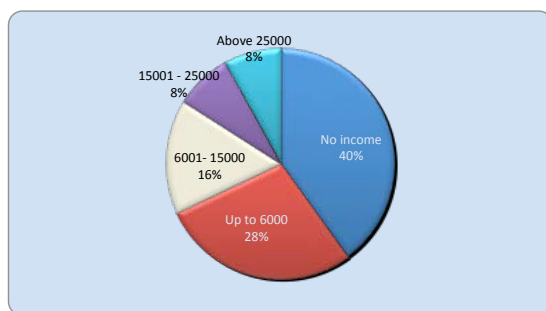


Figure 3.1.5: Patient income levels

### 3.1.6 TB Diagnosis

#### Drug-Resistant TB

Tuberculosis (TB) is a disease caused by bacteria (*mycobacterium bacillus*) that are spread from person to person through the air. TB usually affects the lungs, but it can also affect other parts of the body, such as the brain, the kidneys, or the spine. In most cases, TB is treatable and curable; however, people with TB can die if they do not get proper treatment.

MDR (multi drug resistant) TB is the name given to TB when the bacteria that are causing it are resistant to at least isoniazid and rifampicin, two of the most effective TB drugs.

XDR TB (extensively drug resistant TB) is defined as strains resistant to at least rifampicin and isoniazid in addition to being resistant to one of the fluoroquinolones, as well as resistant to at least one of the second line injectable TB drugs amikacin, kanamycin or capreomycin.<sup>3</sup>

MDR TB and XDR TB do not respond to the standard six months of TB treatment with “first line” anti TB drugs, and treatment for them can take two years or more and requires treatment with other drugs that are less potent, more toxic and much more expensive. Worldwide only a few thousand patients with MDR TB and XDR TB are treated each year

Drug susceptible TB is the opposite of drug resistant TB. Drug-susceptible TB can be cured within six months; and treatment is effective with all the TB dugs so long as they are taken properly.

Of the 25 people affected by TB sampled, 80% were diagnosed with Drug Susceptible (DS TB) while 20% (12% were diagnosed with drug resistant (DR TB). Furthermore, 68% of the patients had pulmonary TB and 32% had extra pulmonary TB. These figures are shown in Table 3.1. Based on the sampled population, DR TB is more common with patients presenting with extra pulmonary TB.

15. Doyle C et al, Health impacts of employment: A review, Institute of Public health in Ireland, March, 2006. [http://www.publichealth.ie/files/file/IPH\\_Employment\\_Health\\_24pp.pdf](http://www.publichealth.ie/files/file/IPH_Employment_Health_24pp.pdf)



Form of TB suffered from		Where TB is in the body		Total
		Pulmonary	Extra Pulmonary	
DS TB	Count	15	5	20
	% of Total	60.0%	20.0%	80.0%
DR TB	Count	2	3	5
	% of Total	8.0%	12.0%	20.0%
Total	Count	17	8	25
	% of Total	68.0%	32.0%	100.0%

Table 3.1: Form of TB and its location in the body

### 3.2 KNOWLEDGE OF TB INFECTION, MANAGEMENT AND CONTROL AMONG TB PATIENTS, HEALTH CARE WORKERS AND COMMUNITY MEMBERS

This section looks at knowledge of TB infection, management and control among patients, health care workers and community members. The following areas were covered: TB infection, HIV testing; messaging about TB transmission; messaging about taking TB drugs and diet while on TB treatment and existence and use of national guidelines on management of TB.

#### 3.2.1 Point of first diagnosis for TB patients

Of the 25 TB patients who were interviewed, 72% were diagnosed at government health facilities within Kisumu County; 16% were diagnosed at private hospitals within the county and 12% were diagnosed at government hospitals outside the county. The Government Hospitals received referrals from Most of the referrals to the Government Health Facilities were from private health facilities within the county and some government hospitals outside Kisumu County. The reasons given for transfers/referrals included the fact that the referring facility did not have the requisite equipment for testing TB; affordability of services in cases where the referring institution was a private hospital and the patient could not afford to pay for the services hence the move to a public health facility which has payment for services subsidized; and the distance from their place of residence in that the initial place was far from home and they could not afford the transport to and from the initial facility.

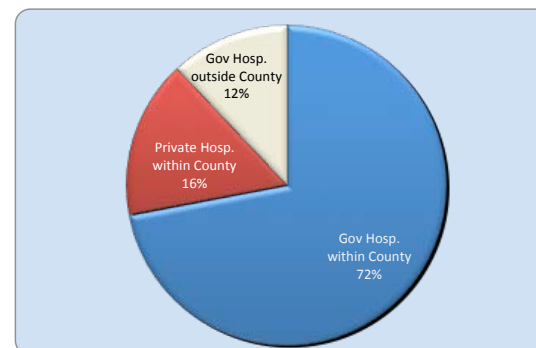


Figure 3.2.1: Point of first diagnosis for TB patients

#### 3.2.2 TB - HIV Comorbidity

Promoting linkages between tuberculosis (TB) and HIV treatment & prevention programs is essential to improve diagnosis, treatment and outcomes for patients affected by both diseases. According to the Interagency Coalition on AIDS and Development<sup>16</sup>, when a person is infected with HIV, they are at an increased risk of also contracting TB. Co-infection with TB can also mean an accelerated progression to AIDS. Increasing the number of PLHIV being tested for all forms of TB is the first critical step to addressing TB-HIV co-infection. Similarly, it is also essential that TB patients have easy access to HIV testing and counseling.

The study showed that 84 % of the patients interviewed mentioned that they were tested for HIV at the same time when they were diagnosed with TB. 16% of the respondents indicated that when they were diagnosed with TB, they already knew their HIV status hence they did not have to undergo another HIV test. Additionally, 30% of the TB patients interviewed tested negative for HIV while 70% tested HIV positive.

According to the 2013 Kenyan Guidelines for Management of Tuberculosis and Leprosy <sup>17</sup>, best practice requires that all persons found to be HIV positive should be screened for TB and referred to the nearest TB diagnostic centers. PLHIV enrolled in chronic HIV care should also be screened for TB. The Ministry opines that intensified TB case finding promotes early TB case detection therefore reducing the duration of disease which - effectively reduces transmission, morbidity and mortality.

16. Interagency Coalition on AIDS and Development (ICAD) & Results Canada, TB /HIV Co-infection Fact Sheet. [http://www.icad-cisd.com/pdf/TB\\_HIV\\_Coinfection\\_ENGLISH.pdf](http://www.icad-cisd.com/pdf/TB_HIV_Coinfection_ENGLISH.pdf)

17. Government of Kenya, Ministry of Health, Guidelines for Management of Tuberculosis and Leprosy in Kenya, July, 2013. [http://www.nhpf.co.ke/docs/TB\\_Treatment\\_GUIDELINES\\_2013.pdf](http://www.nhpf.co.ke/docs/TB_Treatment_GUIDELINES_2013.pdf)

### 3.2.3 Knowledge of TB infection and management

When respondents were asked how TB is transmitted, they gave responses that are collated as shown in Table 3.2.3. A total of 41% mentioned that it is transmitted by air; 20.5% mentioned coughing without closing one's mouth with handkerchief therefore transmitting it to the next person; 10.3% mentioned sharing utensils/food/cigarettes; another 10.3% mentioned being near an infected person/sharing bed; 7.7% mentioned spitting carelessly and 2.6% mentioned sharing poorly ventilated house with an infected person. Also, 81.5% of the care givers know how TB is transmitted.

How TB is transmitted	Responses	
	N	Percent
By air	16	41.0%
Coughing without closing mouth with handkerchief	8	20.5%
Sharing utensils/ food/ cigarettes	4	10.3%
Being near an infected person/sharing bed	4	10.3%
Spitting carelessly	3	7.7%
Sharing poorly ventilated house with infected person	1	2.6%
Don't know	3	7.7%
<b>Total</b>	<b>39</b>	<b>100.0%</b>

Table 3.2.: TB transmission

Despite above 80% knowledge of TB transmission, 3% of the respondents did not know how the disease is transmitted. Two of these patients had been referred to one of the respondent health facilities from a government facility outside the county and one was from a facility within the county and was diagnosed with DR TB. TB is known to be highly infectious and information about its transmission and prevention should be well known to both the patients and caregivers. In this study we came across:

**Case 1:** A grandmother who had TB infected her six month old grandchild who she used to babysit.

**Case 2:** A patient who had interrupted her treatment regimen: - Achieng' (not real name) had been taking TB medication at a health facility in Mutongwe. Since she was diagnosed with TB when she was still strong, she did and still does not believe she has TB. When she returned home, she stopped taking medication. As a result she infected her brother and father who are now both dead. Hospital X forcefully

intervened and isolated her for a while giving her injections. She again broke loose and disappeared after getting 59 injections. It took the health care providers some time to trace her and get her back to medication.

Even though cases highlighted represent a small fraction of the population because the sample interviewed was small, there is need for the population to be educated on TB transmission and prevention. County TB, Leprosy and Lung Health Coordinator, Dr. Malika Timothy indicates that when the right information is given at the commencement of the treatment, there is high likelihood that this patient will complete treatment successfully. The importance of TB literacy can therefore not be understated.

Looking at the responses received from the patients, it is clear that they are not very well informed on the modes of transmission and there is a lot of misinformation on the transmission of TB among the patients who took part in the study in Kisumu County.

On the other hand, 90% of the health care providers mentioned that during the course of their work while attending to TB patients, they have enough time to relay information on TB, ranging from infection to control, transmission, drug side effects, treatment adherence and the effects of failure of treatment adherence. The inconsistency about information from patients and health care workers highlights the need to re-assess communication channels or the packaging of TB transmission information.

#### 3.2.3.1 Knowledge on taking TB drugs

The messaging from the responses received during the study was about three things as shown in the key messages. Eat before taking TB drugs to minimize side effects; choose the time to take the drugs and stick to it throughout the treatment period, and; rest awhile after taking medication. Most of the messages failed to emphasize the exact timing; the patients did not have any information on the side effects of the drugs even though this is one of the factors that they cited as a reason for their interruption of medication. One of the cases the study found was:

**Case 3:** Point of drug dispensation: Odhiambo (not real name) is on TB drugs. He is addicted to 'miti ni dawa' (name given to a local brew) that his community health care worker has to consistently go after him with medication to the drinking dens.

The patients, in their responses, indicated that they had been informed of the importance of completing the dosage and maintenance of specific timings for taking TB drugs so as to avoid developing resistance to the drugs, avoid re-starting the dosage, and ensuring full recovery.

### 3.2.3.2 Recommended diet while on TB treatment

The study showed that 72% of the patients were informed of the diet recommended during the time they were on TB treatment. This information was received by the patients when they were diagnosed with TB at the health facility. 28% of the patients did not receive any information on what specific diet to keep during the treatment period. Among the patients interviewed, 60% of them adhered to the advice given on the dietary requirements while 40% of the patients did not adhere to the requirements as advised. Among the reasons given by the 40% who did not adhere to the dietary requirements was the fact that they could not afford the food ingredients required. They argued that their meager income could not allow them to spend the extra amounts on the special diet required. Once again, there is need to keep repeating medication, control and dietary information.

### 3.2.4 Knowledge on the existence and use of National Guidelines on Management of TB

At the health facilities 80% of nurses/clinicians and 29.6% of care givers knew about the GOK policy on TB prevention and management. Besides, the health care workers were conversant with the daily processes of diagnosis (history, physical examination and investigations), counseling and treatment with a lot of emphasis on adherence. The National Guidelines on Management of TB in Adults and Children (2013) are intended to guide the health care workers in delivery of TB Services.

### 3.2.5 Patients understanding of human rights and TB management

When the TB patients were asked to state what they understand by the term human rights, they had these responses:

- Access to healthcare, right to be listened to and be given information
- Basic entitlement that a human being enjoys
- Freedom to do what I want e.g. taking medication from any facility
- 'Haki yangu' – my rights
- The right to ask questions and be given information as per the universal rights
- Have heard of it, but does not understand what it means
- Right to healthcare, other services and to privacy
- Right to human expression and to access TB drugs
- The right for you to do what you feel is right
- The rights that protect one
- There is right to health, information, to give opinion as long as I don't abuse anybody
- What one deserves/ what one is entitled to

- What one deserves to get as basic e.g. right to information and access to healthcare

The existence of a problem was noted not only with the patients but also with the health care workers as they both knew very little about human rights and the human rights based approach to service delivery. Both groups of people could not define what human rights meant and how they can be violated and /or even protected.

## 3.3 PERCEPTIONS AND EXPERIENCES OF TB PATIENTS, HEALTH CARE WORKERS AND COMMUNITIES ON TB HEALTH SERVICE DELIVERY AND SATISFACTION.

This section looked at perceptions and experiences of TB patients, health care workers and communities on TB health service delivery and satisfaction. It covers sub headings of: distance to health facility; ratings of services received at health facilities and access to TB drugs.

When a patient suffers from TB there is need for all round support with regard to care and treatment. Access to the health facility for treatment and subsequently food supplements is important to ensure that the patients do not fall out of the treatment cycle. Further, it is important to note that when one is diagnosed with TB, it becomes difficult to continue with their income generating activities or employment until they are declared non-infectious. It is critical at this point that they are provided with food supplements and other enablers like transport to the health facilities. Most of these enablers are only available at the health facility and therefore if the patient cannot get to the facility in the first instance, then they cannot access that critical help.

### 3.3.1 Distance to health facility

One of the causes of interrupted dosage of medication is distance from residence to health facility. In this study, over 80% of the respondents resided within 3 km of the health facility. Only 20% of the respondents had to travel between 20-50 Km to access treatment at the health facility. Some TB patients avoid going to nearby health centers associated with TB diagnosis and treatment for fear of stigma and discrimination, instead seeking diagnosis and treatment at far off health facilities. Others continue with the far off health facilities because that is where they were originally diagnosed.

One of the respondents, affected by TB of the spine, has to travel a distance of about 15 Km daily on a motorcycle to the health facility

for an injection. At some point she had to stop going for the injections because of lack of money. Despite the availability of food supplement given to TB patients with Body Mass Index (BMI) of below 18, one cannot access it without reporting to the health facility.

### 3.3.2 Ratings of services received at the health facilities

Patients were asked to rate the quality of services that they receive when seeking for TB treatment at the health facilities. As shown in Figure 3.7, a total of 64% said the services were good; 28% said the services were fair and some 8% said the services were poor. Some of the reasons cited for poor rating of the services were, that the health care providers had a bad attitude towards them and did not handle the patients well. Some waited for long before they were served.

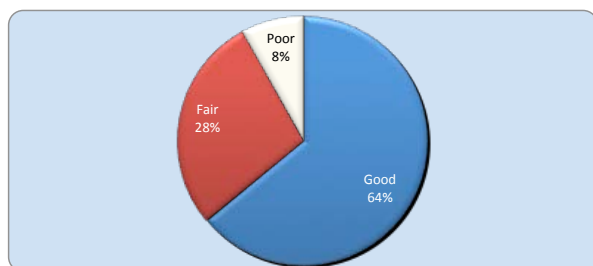


Figure 3.3.2: Patients' rating of services received at health facilities

Besides the general good rating of services received at health facilities, 8% of the patients said the services were poor. Reasons for poor rating were given as: finding a rude health care provider and delayed service yet the treatment (injection) is given at a specific time. After one of the patients complained to her initiator at the health facility through phone, she was served immediately. She still goes for her injection at the same health facility but she is nowadays not delayed. Unfortunately, we cannot say the same for a patient who was talked to rudely, and stopped going to the health facility and also stopped taking the drugs. Fortunately, this patient has been followed and convinced to come back to the health facility for medication and has agreed to do so.

*The National Patients' Rights Charter (2013) states that all patients should have access to health care, the highest attainable standard of health services and the right to information among others.*

### 3.3.3 Access to TB medication

During this study, we came across DS, DR and MDR TB cases. All these cases receive drugs from their convenient health facilities. In an effort to understand reasons for interrupted treatment and the relevance of this to human rights, patients were asked several health access questions. These questions are listed in Figure 3.8

According to the patients, TB drugs are always at the health facilities where they get their medication from. A total of 96% of the patients acknowledged that TB drugs are provided for free at health facilities and 28% continue to receive /had received porridge flour for those with BMI lower than 18. It however emerged that 36% of the patients had to buy TB related medication and that 32% of the patients have at one point skipped medication.

Considering that the reasons given for skipping medication or being lost to follow-up included lack of bus fare to and from the health facility, being very sick, fear of side effects and handling by health care provider, there is need for more enablers, not just food. A patient mentioned that she cannot work in her condition; her husband is a casual worker so whatever money they get is used for her transport to the health facility for treatment, as a result there is hardly any food back at home.

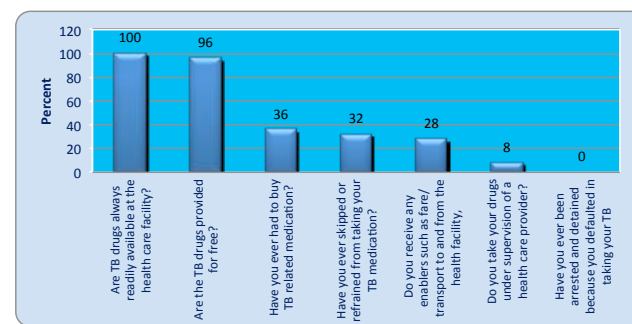


Figure 3.3.3: Access to TB medication



### 3.4 INCIDENCES OF THE BREACH OF THE RIGHTS OF TB PATIENTS IN KISUMU COUNTY.

This section evaluates the incidences of the breach of the rights of TB patients in Kisumu County. It covers issues relating to patients' understanding of human rights and TB management; and Health care providers' and caregivers' understanding of human rights and TB management.

#### 3.4.1 TB patients understanding of human rights and the right to health

When asked what they understood to be the human rights violation of a TB patient, only 44% of the respondents could easily give a response. The responses that were given to signal a violation included:

- Delay in service by healthcare provider.
- Told TB treatment is free but bought injection water
- Doesn't understand but did not like the way she treated me at the facility
- Harassment or stigma
- Have the right to get TB treatment
- I heard that if a TB patient does not take drugs consistently they can be jailed
- If not given right information e.g. I was not given information on TB, how to prevent other household members from getting infected
- Isolating a TB patient
- Not getting medicine, should be told how to take medication, should be diagnosed well to understand the extent of TB in the body
- Some people being given priority when people come to take drugs
- Supposed to get medication with dignity and respect
- When a child is raped, it means that her rights have been violated
- When a patient does not enjoy the right to efficient treatment

For many of the respondents, the right to health meant:

- Accessing care when not feeling well
- As a Kenyan and a human being, I have the right to access healthcare
- I understand that every person has a right to health
- No one can stop the other from seeking medication
- One is supposed to be in good health and must be treated well when accessing healthcare
- Proper treatment and access to drugs
- Right to access basic health care
- Right to know what I am suffering from, drugs I am taking and side effects
- Should get quality treatment at any government facility because we pay taxes

#### 3.4.2 Health care providers' and caregivers' understanding of human rights and TB management

The average number of caregivers who have heard of articles that refer to human rights is 44% whereas that of health care providers stands at 74.5%. Table 3.3 shows that more than half of the care givers have heard of articles 39 (1), 28, 24 (1), 25 (a) and 29 (a) and (d) of the Constitution of Kenya.

Human rights: Have you heard of: -	Care giverHealth Care Provider Yes (%)	Health Care Provider Yes (%)
Article 39 (1): Every person has the right to movement?	70.4	80
Article 28: Every person has inherent dignity and the right to have that dignity respected and protected?	63	90
Chapter IV: Bill of Rights?	59.3	80
Article 24 (1): No fundamental freedom shall not be limited except by law and to the extent that the limitation is reasonable and justifiable?	51.9	80
Article 25 (a): Freedom from torture and cruel, inhuman or degrading treatment or punishment	51.9	80
Article 29 (a) and (d): Right not to be deprived of freedom arbitrarily or without just cause and not to be subjected to torture in any manner, whether physical or psychological?	51.9	90
Section 27: Public Health Act and its provision on notifiable infectious diseases?	40.7	80
Chapter IV: Provisions on the right to health?	29.6	80
Do you know what the GOK policy on TB prevention and management is?	29.6	80
Have you read Section 27 of the Public Health Act and its provision on notifiable infectious diseases?	25.9	60
Do you know what the County Government of Kisumu policy on TB prevention and management is?	11.1	20

Table 3.3: Understanding of human rights by caregivers and Health Care Providers

The study showed that 64% of the patients vaguely understood the meaning of human rights. The weakness was not only with patients

but also with caregivers and community health workers. When asked what they understood to be the human rights violation of a TB patient, only 44% of the respondents could relate. There was very low knowledge by caregivers on Section 27 of the Public Health Act and its provision on notifiable infectious diseases; provisions of Chapter IV of the Kenyan Constitution that contains provisions on the right to health; GOK policy on TB prevention and management and County Government of Kisumu policy on TB prevention and management. Only 20% of the health care workers interviewed knew about the County Government of Kisumu policy on TB prevention and management is.

## 4.0 CONCLUSION AND RECOMMENDATIONS

This pilot study suggests that TB is a significant problem and a major public health concern, not only in the county of Kisumu, but across the country and improving the access to affordable TB diagnosis and treatment and upholding the rights of TB patients is a priority. From the study findings, there is a dire need to place TB patients at the center of their treatment, as equal partners, driving health policy, to participate and claim specific rights.

This study brings out an enormous challenge and an urgent need to revamp reform and repackage TB messaging. It would be better to establish an appropriate control measure such as establishing proper information, education, and a communication pathway for TB. There is need to increase awareness through various communication channels on the cause, transmission, prevention, and availability of public services for treatment. Such awareness campaigns could include talk shows, radio spots, television and other culturally correct channels of communication.

Furthermore, the national and county TB control units should consider coordinating advocacy, communication, and social mobilization activities at the communities to improve knowledge, attitude and perception of TB, to reduce misconceptions, and prevent transmission of TB in the community. To address the human rights implications of TB policy, legislation and programming, it is important to facilitate dialogue among different stakeholders, at both the national and county governments, including provision of affordable diagnostic and treatment for TB for all regardless of socio-economic and legal status.

Specific strategies should be developed, national policies updated and inter-county collaboration ensured. All services for diagnosis and treatment for TB patients should be made available free of charge, including the required ancillary treatment and the social support to those affected.

This is an important measure to ensure treatment adherence, and

social protection of their families to prevent catastrophic expenditures. Laboratory services and hospital care should be consistently improved, including the upgrading and renovation of facilities.

Some of the legal and policy gaps identified are:

- Need for education of TB patients, counties suspected to have TB and the community in general about TB, its prevention and management.
- Need for a coordinated and proper referral mechanism among health facilities within the county that is accessible to all health care professionals.
- Greater budgetary allocation and investment by the County government for TB prevention and management
- Need for continuous professional development of all health care providers on the human rights, the rights based approach and new developments on TB and medicine.
- Need for investment in addressing the social and economic effects of TB

There is need for an integrated and multi-sector response to TB, making human rights an integral dimension in the design; implementation, monitoring and evaluation of TB related policies and programmes. In addition, we need accountability tools for governments, the international community and civil society to monitor the progress of all stakeholders in realizing the right to health. The authorities should address socio-economic determinants of TB and the need for a strategic agenda to pursue a rights-based approach and mainstream a human rights approach.

Given the limited level of understanding amongst the study respondents regarding the human rights legislation related to TB and right to healthcare services, there is a need to engage with stakeholders and communities to provide information and promote discussions around:

- The meaning of human rights violations and discrimination.
- The contents of the Constitution 2010 including the Bill of Rights.
- The content of the Public Health Act Chapter 242 of the Law of Kenya and its provisions.
- All the remedies available to address human rights violations including providing a data base of KELIN trained probono lawyers in the county and linking them to communities

- Further engagement is needed within communities regarding issues of stigma and discrimination against TB patients that arise in the family context. There is a need for community training initiatives related to the meaning of stigma and discrimination, which should also include recommended strategies in addressing the same
- Increase in the level of advocacy and lobbying for law and policy reform with the relevant stakeholders on matters relating to TB, leprosy and lung diseases.

Duty bearers and stakeholders including service providers should also be equipped with the knowledge to identify and address the kind of human rights violations and discrimination suffered by TB patients. These people include:

- **Health officers:** Health officers and medical service providers need to be trained on the rights of TB patients, since health officers are often the first point of contact for TB patients, patients need to be treated with respect and dignity.
- **Chiefs, elders and local leaders, Employers:** For many TB patients in Kenya it is their Chiefs, employers, elders and local leaders who hear their complaints and determine the outcome of disputes regarding rights violations. There is a need for training programs for these community leaders to 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 TB patients. Employers too should be sensitized to provide support programs to the sick and bridge the gap on inadequate knowledge on human rights among the general public and key stakeholders.
- **Communication channels:** Many of the participants demonstrated an understanding of the existence of human rights legislation offering protection to TB patients, but they were not aware of the details. This suggests that previous media campaigns to raise awareness on these issues have not reached the target population. There is a need to ensure that the channels of communication to reach TB patients and affected communities are accessible to the target population. Printed educational materials should be produced in a simple format and language with possible translation into local languages. Relevant legislation such as the Constitution of Kenya 2010 including the Bill of Rights, and the the Public Health

Act, patients charter should be provided to TB patients and their communities in an easily accessible format through production and distribution of popular versions. Consideration needs to be given to making the legislation accessible in formats that facilitate the inclusion of the different categories of persons with disabilities like the visually impaired.

There is need to review of laws, policies and law enforcement practices that impact negatively on the TB response, taking into account the human rights and gender gaps. On access to justice, the majority of participants felt unable to seek redress for human rights abuses they had experienced as a result of their health status. There is a need to ensure that TB patients have better access to justice in both law and practice. TB patients need to be provided access to legal aid to enable them to access legal representation to bring challenges against human rights violations and discrimination cases.

TB patients support groups are instrumental in providing information, and as well as offering vital emotional and social support, these groups are often the first points of contact for TB patients seeking redress for human rights violations. These groups need to be provided with training and resources so that they are equipped to identify human rights violations and make appropriate referrals.





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KEMRI/RES/7/3/1

April 15, 2015

TO: **BELICE ODAMNA (PRINCIPAL INVESTIGATOR)**  
**KELIN,**  
**P.O. BOX 112-00202, KNH,**  
**NAIROBI, KENYA**

Dear Madam,

RE: **NON-SSC PROTOCOL NO. 478 (RESUBMISSION 2-INITIAL SUBMISSION):  
A PILOT STUDY TO EVALUATE THE EXPERIENCE OF TB PATIENTS WHEN  
ACCESSING TB SERVICES – (VERSION 3 DATED 10<sup>TH</sup> APRIL, 2015)**

Reference is made to your letter dated 15<sup>th</sup> April, 2015. KEMRI/Scientific and Ethics Review Unit (SERU) acknowledges receipt of the revised study protocol on the same day.

This is to inform you that the Committee notes that the issues raised at the 236<sup>th</sup> meeting of the KEMRI/Ethics Review Unit (ERC) held on 17<sup>th</sup> January, 2015 have been adequately addressed.

Consequently, the study is granted approval for implementation effective this day **15<sup>th</sup> April, 2015** for a period of one year. Please note that authorization to conduct this study will automatically expire on **April 14, 2016**. If you plan to continue data collection or analysis beyond this date, please submit an application for continuation approval to SERU by **March 03, 2016**.

You are required to submit any proposed changes to this study to SERU for review and the changes should not be initiated until written approval from SERU is received. Please note that any unanticipated problems resulting from the implementation of this study should be brought to the attention of SERU and you should advise SERU when the study is completed or discontinued.

You may embark on the study.

Yours faithfully,

**PROF. ELIZABETH BUKUSI,**  
**ACTING HEAD,**  
**KEMRI/SCIENTIFIC AND ETHICS REVIEW UNIT**

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