THE PATIENT'S RIGHT TO PARTICIPATION. A KEY FACTOR IN IMPROVING THE QUALITY OF HEALTH SERVICE DELIVERY IN UGANDA. A CASE STUDY OF MASAKA DISTRICT.

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THIS RESEARCH REPORT HAS BEEN SUBMITTED TO THE COLLEGE OF HUMANITIES AND SOCIAL SCIENCES IN PARTIAAL FULFILMENT OF THE REQUIREMENT

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DECLARATION

I hereby do declare that, this is my original work and it has never been submitted to any higher Institution of learning.

.....Ponny.....

ZAINABU PONNY LAKO

APPROVAL

This work has been under my supervision and it is now ready for submission.

SUPERVISOR



07/08/2013

OKURUT GODFREY.

DEDICATION

This work is dedicated to my family members, my husband Antony Leju, Asaiah Ladu, Eddie.

ACKNOWLEDGEMENT

I would like to thank my husband Antony Leju for paying my fees and also allowing me to study, my classmates or colleagues for their cooperation.

I would like to thank the almighty God for enabling me through.

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ABSTRACT

The right to participation is one of the key human rights in the protection and promotion of human life. According to the United Nations General assembly as reflected in the Universal Declaration of Human Rights, the right to participation is one of the highest inspirations of common people.

Healthcare world over has transformed from the medical approach of the first half of the 20th century, where a patient was considered only a passive user of health services and the doctor who was the expert knew all. Patients therefore had no right to question the services they received or took part in the decisions made on their lives. With the development of the human rights regime, the following Universal Declaration on Primary Healthcare (1976), the consumer is considered a significant partner in the delivery of health services. With the notion of primary healthcare and the right-based approach, patients are entitled to know and participate effectively in the management of their health system. The right to participation is therefore a key preliquist for the consumers to manage their own health and the delivery of quality services. When viewed from a more modern perspective, healthcare is increasingly becoming a commodity subjected to the Neo-Keynesian rules of demand and supply as consumers are paying for services they receive. It therefore becomes both a legal and moral imperative that patients who are buyers of health services have adequate participation and their efforts must be seen regarding the services they receive. Some countries like United Kingdom, France, and

South Africa have gone ahead to provide legislation on the right to participation both in private and public sector.

However, there is no legal framework for patients rights particularly right to participation at health facilities considering the wide spread outcry on the poor quality of services in the country. In absence of a clear legislation and adequate information one wonders how patients can claim for their rights about the services they receive and make informed decisions about services they receive.

This research therefore was prompted to review the existing mechanisms and assess how the right to participation is promoted at health facilities in Uganda today and prompts policy intervention.

The research was carried out in Masaka District and it covered Masaka Refferal hospital in the category of a public hospital, Kitovu hospital in the category of private not for profit and Kimwanyi Health Centre IV in the category of private for profit. It is hoped that the results presented in this report can become a useful tool in the implementation actions to empower patients right to participation and improve the quality of health care in Uganda.

The research was designed to find out how the patients' right to participation can improve the quality in the delivery of health services.

Sample Selection - Masaka District

Health unit	Type of provider	Size of health unit	Sample
Masaka Hospital	Government	Big (NRH)	18
Kitovu Hospital	NGO	Big (HC IV)	18
Kimwanyi Health Centre	Private for Profit	Big (HC IV)	18
Total			**54**

Major Survey Findings

The proportion of patients who claim that patients have rights could be interpreted as a general headline indicator for the level of rights awareness. However, some patients would simply claim that patients have rights without being able to mention a single one of them, this was especially the case in Kitovu Hospital and Masaka Referral Hospital. The right to participation was therefore given emphasis as the *patients claiming to have rights who were unable to identify the right to participation.* According to this indicator, rights to participation can be said to be significantly higher in Private health centres than in public hospitals.

Almost half of respondents are still not aware of feedback mechanisms at health facilities. Furthermore, from the figure above, we note that of the total number of people who are aware of the existence feedback mechanisms (the majority mentioned a doctor or a nurse as the available feedback mechanism, rather than an intended avenue such as the suggestion box or complaints desk. This suggests they may assume the doctor or nurse is

CHAPTER ONE

INTRODUCTION

1.0 Over View

The existence and effectiveness of patient's rights is crucial in the quest for the improvement in the delivery of quality health services. Although it is pertinent in observing all patients' rights that have been so far defined (UNHCO 2002), it is especially important in fulfilling two of these rights.

- The right to redress – "Every patient has a right to redress and have their grievance addressed by health institutions."

- The right to participation – "Patients have the right to be participate in matters of planning and management of the affairs of their own health care as individuals and through chosen representatives."

In this research on the Patient's Rights to participation, it was found out that almost none of the health users interviewed recognized the right to participation.

Community participation and empowerement are critical aspects of the HSSP and overall Government strategy for poverty reduction. According to UPPAR (2000) "Among the social aspects responsible for poverty is the absence of social support, creating a feeling of isolation and exclusion, powerlessness, deprivation of basic human rights and a feeling of helplessness to influence the conditions around oneself". If we are to empower patients to participate and take responsibility for their health, there must be mechanisms in place whereby the health consumers can provide feedback to the people that provide them with health care. Otherwise, the consumer will remain marginalized from his/her health concerns and the sole responsibility of health care will remain with the provider.

1.1 Background to the study

The right to participation is one of the key human rights in the protection and promotion of human life. According to the United Nations General assembly as reflected in the Universal Declaration of Human Rights, the right to participation is one of the highest inspirations of common people. The United Nations High Commissioner for Human Rights discerns participation in national development...the *challenge is facing both the human rights community and public health professionals.* (United Nations High Commissioner for Human Rights, Mary Robinson, quoted by WHO, Health and Human Rights publication series, issue No. 1 July 2002). For patients, the exercise of the right to participation would help them deal with their individual health problems and improve on the management of healthcare. However, the enjoyment of

the right to participation at health facilities is related to the general development of the health care system in terms of access to health facilities, availability of drugs, qualified personnel, institutional structures in place and enjoyment of other rights which include among others equal access to treatment, respect, privacy, safety, right to chose and self determination. These rights are sine-no-quo for utilizing the right to participation at health facilities for someone without access to hospital, cannot exercise the right to participation. Nonetheless, the right to participation and health are fundamental rights reflected in all international and local human rights instruments. (UDHR; Article 21(1), ICESR; Article 15, CERD; Article 5, CEDAW; Article 7, 8, 13, 14, CRC; Article 3, 9, & 12, Ugandan Constitution Article 36).

Healthcare world over has transformed from the medical approach of the first half of the 20th century, where a patient was considered only a passive user of health services and the doctor who was the expert knew all. Patients therefore had no right to question the services they received or took part in the decisions made on their lives. With the development of the human rights regime, the following Universal Declaration on Primary Healthcare (1976), the consumer is considered a significant partner in the delivery of health services. With the notion of primary healthcare and the right-based approach, patients are entitled to know and participate effectively in the management of their health system. The right to participation is therefore a key preliquist for the consumers to manage their own health and the delivery of quality services. When viewed from a more modern perspective, healthcare is increasingly becoming a commodity subjected to the Neo-Keynesian rules of demand and supply as consumers

are paying for services they receive. It therefore becomes both a legal and moral imperative that patients who are buyers of health services have adequate participation and their efforts must be seen regarding the services they receive. Some countries like United Kingdom, France, and South Africa have gone ahead to provide legislation on the right to participation both in private and public sector.

On the local scene in Uganda, the right to participation as provided for in the constitution (Article 36) has not yet been promulgated into a law for its enforcement. It has been challenged for only embracing participation in the political arena. For critical areas like health, there is no legal backing in place to ensure patients' participation apart from ratifying the ICCPR, ICESCR, and other international instruments that provide for the right to participation and health. To improve the lives of the poor Ugandans demanded by the Millennium Development Goals and the 5^{m} Pillar (Human and Development) of the draft PEAP 2004, the country is required to increase support to the health sector through better programmes to increase drug supply, Home based management of malaria, improving reproductive health, combating HIV/AIDS, addressing aspects of gender and carrying out awareness programmes.

In order to address health rights in Uganda, and to improve the lives of the poor as delineated in the Poverty Eradication Action Plan (PEAP), government has been promoting the Health Sector Strategic Plan (HSSP) with emphasis on the minimum healthcare package since 1999, while PEAP is the overall national planning

framework, HSSP is the comprehensive strategy for improving the quality of life by promoting the National Health Policy objectives. Ill health has been identified by the poor as the main cause and consequence of poverty especially in the rural areas where vulnerable groups like women, children and the persons with disabilities live. Uganda's health sector has suffered numerous upheavals from the total collapse in the 70's and 80's where there was virtually no concern for provision of drugs in public facilities and the general disregard for patients' rights. The initiatives of both Government and private sector to combat the disease burden through sector wide approaches have not decreased the morbidity and mortality rates with 75% of Ugandans dying from preventable causes. The coverage of health facilities has increased from 43% to 49% of parishes but the toll of malaria, HIV (6.5%) on the population, maternal and infant mortality is still high and people are not effectively utilizing available services due to lack of participation and awareness.

Without information, and community empowerment on their rights, disadvantaged people like women on their rights would continue staying away from the existing health services that are even still under funded. According to the provisional Mid Term Expenditure Framework (MTEF), the health budget is set to be sliced from 218.8 bn to 214.0 bn implying a reduction of 4.77 Bn and per capita reduction in health spending by 11% yet Uganda, spends about US $1.20 per capita on drugs less than a poorer country Mozambique (US $2 per capita).

1.2 Statement of the problem

Uganda has ratified all major conventions relating to the right of participation and health including the ICCPR, ICESCR, CEDAW, and CRC and even domesticating the right to participation in the constitution (Article 36). However, there is no legal framework for patients rights particularly right to participation at health facilities considering the wide spread outcry on the poor quality of services in the country. In absence of a clear legislation and adequate information one wonders how patients can claim for their rights about the services they receive and make informed decisions about services they receive. This research prompted to review the existing mechanisms and assess how the right to participation is promoted at health facilities in Uganda today and prompts policy intervention.

1.3 Hypothesis

Owing to the existing framework for promotion of patients rights to participation, this study avoided hypothetical prepositions but sets out to generate answers to the following questions: -

- What mechanisms are in place for promoting the right to participation at health facilities in Uganda?
- What kind of participation is availed to patients?
- Are there any exemptions on the patients right to participation, and what is the basis for these?

- Do patients know about their right to participation at health facilities?
- How do patients exercise their rights at health facilities?
- Are patients satisfied with the health services they receive?
- What measures should be taken to improve on the right?

1.4 Definition of Key Terms

Patient: Person seeking or using health services.

Right to Participation: Freedom to play an active, free and meaningful role.

Health: State of physical, social and mental well being.

Quality Health:

Health Facility: Approved area where health services are provided.

Policy Makers: Officials in control of Government plans/programs.

Consumers: Users of health services.

Special interest groups: persons requiring special attention due to their physical, mental and social disadvantage.

Feedback Mechanisms: Procedures in place to receive and disseminate comments from patients and health workers.

Provider: Health worker

In – Patient: Sick person residing in the health facility for treatment

Out – Patient: Person receiving treatment in a health facility as a non-resident

1.5 Purpose and objectives of the study

This study focused on how the patient's right to participation are promoted at various health facilities in Uganda.

The study specifically attempted to;

1. Identify the range and the nature of mechanisms in place to protect and encourage participation at health facilities.
2. Provide an insight on the nature and category of patient's participation and existing exemptions.
3. Assess the level of awareness among patients and providers on the patients right to participation and other related rights.
4. Provide suggestions for improving the promotion of the right to participation and health rights in general.

The basic idea of the research is that it attempted to establish trends in the quality of health care in respect with the patients' right to participation and also the general awareness about patient's rights in Uganda.

1.6 Significance of the study

The current health services are appalling with life expectancy of 42 years, 75% deaths are caused by preventable diseases and HIV/AIDS, low hygiene and nutrition levels, 505/100,000 and 88/1000 maternal and infant mortality respectively, 49% of parishes with health facilities (UDHS 2000 – 01), and a wide spread outcry against attitudes of some health workers that abuse and deny patients especially mothers the right to participation, by exposing what is happening to the right to participation at health facilities, this research will help to increase the level of the right to participation and correct the review of HSSP to include patients rights.

1.7 Scope of the study

The study was conducted in selected health facilities in Masaka District in categories of Public, Private Not for Profit (NGO), and Private for Profit for purposes of comparison. Direct interviews were done on discharged in and out patients. Two focus group discussions were conducted for representatives of interest groups (community leaders, councilors, elders, women, youths, religious leaders, traditional healers, persons with disabilities) at the health facility to get a deeper understanding of participation through sharing views. Key informants were 2 doctors from each of the selected facilities, policy makers, District Directors of Health services, Rights advocacy NGOs and academicians for technical understanding of the health system and the right to participation in Uganda.

The study focused on the right to participation as the main subject of inquiry at health facilities by looking at the mechanisms in place, exemptions, level of awareness on the rights by patients and their satisfaction by the quality of services provided.

The research lasted six months with one month of pilot field exploration and sorting out administrative issues, 2 months of data collection and 3 months of data analysis, processing and presentation.

1.8 Justification

This research on patients right to participation at health facilities focuses on a special area of patients' rights that are fundamental for consumers to take charge of their own health. It is particularly necessary to collect information from the actual users of health services (Patients), providers and key interest groups to get the true picture of what is happening. This study examined the existing mechanisms at not only public but also private facilities as the later (private) are now also recipients of public funds (PHC). This is therefore an attempt to unearth what is happening with regard to the formation of the prevention of the patients' right to participation at health facilities as a specific subject of investigation.

1.9 Limitations of the study

One of the major challenges for this research undertaking was on the penetration of the technical area of the medical field where information might not be easily obtained.

Another challenge was on training respondents who were already fatigued by ill-health (patients). The researcher however through the collaboration with health workers tried to set appropriate time with each interview especially in-patients. Those in critical conditions were skipped and instead their attendants will be interviewed. Outpatients were captured after obtaining the services.

There was also a constraint of traveling long distances and fixing appointments with interviewees. However, this was dealt with the help of a local guide and research assistant who were involved in the field.

Given the budget and time constraints of the research, it was decided to interview health users directly at the health units immediately after treatment. The major advantage of this approach is that the respondents have a good recollection of the treatment they received. The minimum age for respondents was set to 15 years in order to ensure that the respondent understood the questions being asked. The interviews were conducted at 3 different health units in Masaka District through random sampling. The randomness of the sample is critical to ensuring that the sample adequately describes the characteristics of the different types of patients receiving

treatment. Despite the fact that most respondents were ill at the time of the interview there was a remarkably high response rate and only few interviews had to be interrupted because respondents lost patience since they were not feeling well.

CHAPTER TWO - LITERATURE REVIEW

2.0 Introduction

This section begins with the examination of the various human rights instruments at international, regional and local level and how they depict the right to participation in general and patient's rights in particular. Research works and policy documents that relate to the patients rights and the quality of health care will also be reviewed to adequately address their relationship with the right to participation.

2.1 Human Rights instruments relating to the right to participation and health

The right to participation and health are rooted in all major human rights instruments including; the UDHR (1948); ICCPR (1966); ICESCR (1966); CEDAW (1979); OAU convention (1980) and CRC (1980). On its part, the UDHR provides the foundational elaboration on the right to participation from which other instruments derive.

The UDHR in its preamble further regards participation in general and the right to participation in particular, as the highest aspiration of common people. Though the UDHR is not a binding treaty, as it does not state obligations on the rights, it forms the basis for binding convenants like the ICCPR and the ICESCR. The ICPR (1966) as a binding instrument imputes duties on member states to uphold on participation. The

Review 2003:65). All these were planned for in HSSP I (2001 – 2005: 79-80) but have never had been affected.

2.3 Health participation and promotion of patients' rights in Uganda.

The mission of the national health sector is the *attainment of a good standard of health for all Ugandans in order to promote a healthy and productive population* (State of Uganda's Population Report 2003:16). The health sector strategic plan also recognizes the significance of participation through community empowerment to manage their own health but according to the HSSP Mid Term Review Report (2003:4) and PEAP review (2004) there is big gap in community participation due to lack of awareness, which has negatively affected the efforts to improve the quality of life.

The Health Information Management Systems (HIMS 2003) and Yellow Star Program of the Ministry of Health list participation as part of quality services, but patients do not seem to participate. However, the guideline listed in the HIMS seemed only intended to help service providers and managers to compile all the necessary information on their patients, provide treatment and refers them at times without the patients' participation (HIMS 2003:13). The existing framework for ensuring participation and protection seems to explain the medical model where a patient is viewed as a passive recipient rather than a partner in healthcare. For a more contemporary outlook, these procedures need to be assessed and this research offers some substantial strides of inquiry.

According to the (UNHCO 2002) baseline survey on patients' rights in Uganda, 60 of patients are unaware of the rights at health facilities and another research by the same organization in 2003, revealed that 90% of patients did not know where to make suggestions or complaints hence lack of participation.

The Human Rights Commission Report could not establish the right to participation as to whether it is the most abused or violated. According to the report, the most violated right is the right specified was access to drugs. Yet the same HRC findings indicate the lack of understanding of prescription given to patients as in case of Apac district where 92.3% of respondents did not understand information on the information chit (HRC Report 2003:19). This lack of understanding is partly contributed by the shorthand medical language, yet the report still does not give alternative guidance to ensure that patients' do participate in order to understand the prescriptions given to them.

Therefore, as the right to health does not imply the right to be healthy, but everyone needs a legal protection to the right to participation so as to safe guard his or her own health, the basis and procedures for providing useful participation therefore needs to be explored.

CHAPTER THREE - METHODOLOGY

3.0 Introduction

This section in this research was used to guide the methodological aspects of the study, research design, sample selection, instruments to be used, methods of data collection analysis and presentation. Other related aspects like pre-field activities, quality control and a highlight of the various processes of the research methodology is made.

3.1 Area of study

This was basically a case study that was carried out in Masaka District, which is located in the central Uganda, 125 kms from the capital city. The district has 5 health sub districts, with 2 hospitals, several health center IVs, Health center IIIs and IIs that are located at sub county and parish level respectively (see MOH inventory 2003). The population's major economic activity includes crop farming, cattle keeping, and petty trade, fishing at a limited scale. Therefore, the study was carried out at 3-selected health facilities at referral level HC IV and HCIII that have both out patient and in patient departments.

3.2.Research Design

As a case study of health facilities in Masaka district, the researcher endeavored to generate both qualitative and quantitative data about mechanisms in place for the promotion of patients' right to participation and utilize the experience of providers and consumers to generate the basis to examine the status of the right to participation and patients' rights in general. Qualitative data was to boost the statistical patterns on the collected information and various impressions were followed up to relate to the general progress on the right to health participation in Uganda. Key health officials were interviewed in each health unit in order to obtain additional qualitative information. Health officials were asked questions regarding the patients' rights in general and more specifically the right to participation and their observance at their respective health facilities. The interview also included additional questions regarding ways of ensuring that the rights of patients are emphasized, the kind of participation that would be desirable for the patients, and the measures that would be taken to improve the patients' right to participation.

3.3.Population of the study

The study focused on patients as consumers of health services in the selected health facilities in Masaka district which was chosen due the proximity for the researcher to follow-up on the investigation and its composition that has the urban relatively well informed and the rural generally uninformed poor.

3.4.Sample Selection

The case study randomly capture 54 patients from the health facilities using luster and multi stage methods of obtaining respondents, from the three categories of Public, Private for Profit and Private not for profit.

Health workers were interviewed at each health facility to cross check the information provided by patients.

Two focus group discussions of 15 participants were held to boost the understanding of the right to participation. These included interest groups (women, community leaders, disabled, health workers)

Interviews with senior health officials were done, picking informants for the Ministry of Health (commissioner clinical services, public private partnership and planning department), plus the district health teams and the health advocacy NGOs and Human Rights Activities.

3.5.Data Collection, processing and Analysis

Data collected from the interviews with patients, health workers, and focus group discussions and in depth interviews with key informants shows the qualitative and quantitative data.

Additional materials have been got form secondary data from publication, policy bonus, etc. The use of the interview schedule for all interviews and an observation checklist for cross checking physical aspects were also used.

CHAPTER FOUR – MAJOR SURVEY FINDINGS

THE RIGHT TO PARTICIPATION

Participation refers to the access patients have to be a part of health related affairs such as meetings, organizations, civil society groups or institutions. From this participation, patients can actively elect representatives who will then be able to access and influence government policy. An example of this type of participation can be found in the Community Based Organizations (CBO), which in many cases are in charge of the management of health units at the sub-county level. "Patients have the right to be represented in matters of planning and management of the affairs of their own health care as individuals and through chosen representatives."

I was about to deliver and the doctors told me to keep quiet or they will go away. But the pain was too much and I had to shout. Then they left. By the time they came back I had already delivered and I was pulling the umbilical cord to clean myself from inside.

UNHCO BASELINE SURVEY ON PATIENTS' RIGHTS (Page 9).

Most people would feel sympathy with this woman, so clearly expressing a very critical situation in her life, where she needed good health care the most, but was left alone. The example shows that this woman's right to participation was violated, and this despite the fact that she was delivering at a Hospital where she paid for the health service.

The research was carried out in Masaka District and it covered Masaka Refferal hospital in the category of a public hospital, Kitovu hospital in the category of private not for profit and Kimwanyi Health Centre IV in the category of private for profit. It is hoped that the results presented in this report can become a useful tool in the implementation actions to empower patients right to participation and improve the quality of health care in Uganda.

The research was designed to find out how the patients' right to participation can improve the quality in the delivery of health services.

"*Patients have the right to receive the best possible treatment. To request the assistance and support of medical practitioners whenever necessary. To select their own doctor and medical institutions and to change them, and when they change they*

have the rights to request for information about their examination by previous doctors and to be provided with copies of their records". (UNHCO, 2002).

The research administered a questionnaire patients and 54 patients were interviewed. The research also sought some information from health workers from the 3 sampled health units through the interview guide for key informants. Patients were interviewed at the clinic were they received treatment, and this allowed direct triangulation with the answers from the health care providers. As mentioned earlier, this research administered a Questionnaire, where the respondent is a patient, and a Questionnaire for key informants, where the respondent is a health worker (typically a doctor or a nurse) and some questions for focus group discussions. These are reproduced in Appendix.

4.1 Sample selection in Masaka District.

The implemented sample (see table 1.1) covers 3 health units in Masaka. The total sample was 54 – of these 18 interviews were conducted in all the three selected health units.

Table 4.1 Sample Selection - Masaka District

Health unit	Type of provider	Size of health unit	Sample
Masaka Hospital	Government	Big (NRH)	18
Kitovu Hospital	NGO	Big (HC IV)	18
Kimwanyi Health Centre	Private for Profit	Big (HC IV)	18
Total			54

Below is the information on the demographic and socio-economic characteristics of the respondents (health users) that were interviewed in the research, such as age, sex, educational attainment, religion and occupation.

4.2 Sex of respondents

During the research, an unequal proportion of women were interviewed that men.

Table: 4.2 Sex of respondent (percent distribution)

Sex	Masaka Referal Hospital	Kitovu Hospital	Kimwanyi HC
Male	48.7	36.0	43.8
Female	51.3	64.0	56.2
Total	100.0	100.0	100.0
Number	**18**	**18**	**18**

4.3 Age of respondents

The age distribution of the respondents in the research was of (adults above 15 years). There are relatively more respondents in the age group 15-30 years than in the other two age groups, with the group above 46 years old being the smallest.

Table 4.3 Age of respondent (percent distribution)

Age group	Masaka Referal Hospital	Kitovu Hospital	Kimwanyi HC
15-30 years	66.0	53.3	55.5
31-45 years	22.7	28.0	33.6
46+	11.3	18.7	11.0
Total	100.0	100.0	100.0
Number	18	18	18

4.4 Educational level of respondents

Below is the educational distribution of the sample. Where differences occur, these can be explained by the fact that the population in Masaka Referal Hospital and Kitovu Hospital is relatively better educated than the population in Kimwanyi Health Centre.

Table 4.4 Educational level of respondent (percent distribution)

Level of education	Masaka Referal Hospital	Kitovu Hospital	Kimwanyi HC
No education	4.0	22.7	46.6
Primary education	36.0	53.3	18.5
Secondary education+	60.0	24.0	34.9
Total	100.0	100.0	100.0
Number	18	18	18

In addition to information about patient's rights to participation, the research also measured some related aspects of the quality of health care patients had received. These aspects include: evaluation of treatment received, consultation time, and the relationship between the patients' and health worker.

4.6 Evaluation of Treatment

Table: 4.6 Patient's evaluation of treatment (%)

	Masaka Referal Hospital	Kitovu Hospital	Kimwanyi HC
Good	65.7	61.3	70
Bad	20.7	26.7	10
Not Sure	13.6	12	20.
	100	100	100
Number	18	18	18

Source: Appendix A.

A majority of patients feel that they receive *good* treatment. Some even said to have received *good* treatment. Between 7 and 15 percent evaluate the treatment as *acceptable*. A good percentage of the patients described their treatment as *bad*. Judged by face value, these statements suggest that the quality of health care in Uganda still has a room for improvement. However, patients' evaluations depend on their expectations and knowledge about their right to participation. If people have low expectations and little knowledge about how they should be treated then the figures can be bias.

Certainly, this report has demonstrated that patients' right to participation is frequently violated during treatment, and if patients knew about these rights, then satisfaction rates would be much higher.

The research indicated that there were substantial differences in patients' evaluation of their treatment by socio-economic status. The better-off in Masaka Referal Hospital and Kitovu Hospital were significantly more satisfied with the quality of treatment than the poor. In Kimwanyi Health centre, a majority of the better-off said that services were only acceptable.

4.7 Consultation Time

A consultation typically takes less than 20 minutes according to both patients and providers (see table 4.2). Only 10-25% of the consultations take longer than 20 minutes. This typically shows that there is little or no participation while taking decisions during the delivery of health services between the health workers and the patients.

Table: 4.7 Consultation Time (percentage).

	Patients		
Consultation time	Masaka Referal Hospital	Kitovu Hospital	Kimwanyi HC
0 – 5 min.	20.0	27.3	38.4
5 – 10 min.	23.3	33.3	26.0
10 – 20 min.	30.0	22.0	24.7
20 – 40 min.	19.3	4.0	6.2
40 – 60 min.	6.0	4.0	4.1
One hour or above	1.3	9.3	0.7
Number	18	18	18

4.8 Relationship between the Health Worker and the patients

Table 4.8. Rate your relationship and the health worker who gave you treatment? (%)

	Masaka Referal Hospital	Kitovu Hospital	Kimwanyi HC
Good	95.3	82.7	95.9
Bad	2.7	9.3	3.4
Fair	2.0	8.0	0.7
Number	18	18	18

Source: Appendix A.

The relationship between the health worker was almost universal amongst patients in Kitovu Hospital and Masaka Referal Hospital, while 17% in Kimwanyi Health centre expressed signs of bad relationships. One of the patients in Masaka Referal Hospital explained that during interviews the health staff felt threatened by his presence and denied being interviewed.

4.9 Communication between health workers and patients on sickness and treatment.

Patients have the right to participate while receiving treatment such that the best possible treatment can be given, they also participate by requesting the assistance and support of medical practitioners whenever necessary. To select their own doctor and medical institutions and to change them, and when they change they have the rights to request for information about their examination by previous doctors and to be provided with copies of their records. According to the research, there is very little participation in terms of sickness and treatment, whereby most of the patients in the questionnaire showed that their participation in the selection of a desired health provider is at times very difficult and that they often get problems mostly in the public Hospitals where once the patients' doctor is not around, no service will be given to that patient even when he/she is in extra pain.

Table: 4.9 Communication between health workers and providers about sickness and treatment? (%)

	Masaka Referal Hospital	Kitovu Hospital	Kimwanyi HC
Yes	26.3	30.4	35
No	68.7	58.6	45
Not sure	15	11	20
	100	100	100
Number	18	18	18

4.10 Awareness of patients' rights

The proportion of patients who claim that patients have rights could be interpreted as a general headline indicator for the level of rights awareness. However, some patients would simply claim that patients have rights without being able to mention a single one of them, this was especially the case in Kitovu Hospital and Masaka Referral Hospital. The right to participation was therefore given emphasis as the *patients claiming to have rights who were unable to identify the right to participation*. According to this indicator, rights to participation can be said to be significantly higher in Private health centres than in public hospitals.

Table: 4.10 Aawareness of patients' rights (%)

	Masaka Referal Hospital	Kitovu Hospital	Kimwanyi HC
Yes	4.0	18.7	10.8
No	92.7	60.7	68.5
Not sure	3.3	18.7	20.7
	100	100	100
Number	18	18	18

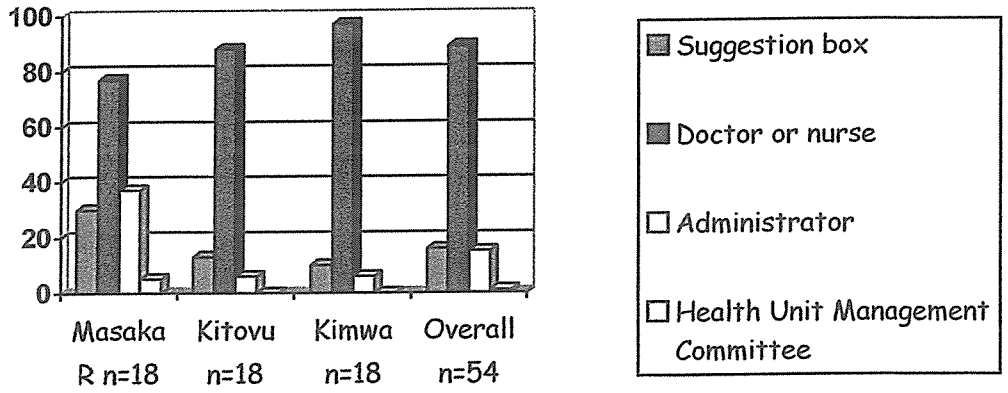
This is also an indication that in general patients are not aware that they have rights and that the right to participation is fundamental that can lead to other rights that include the following:

1. The right to individual respect
2. The right to equal treatment
3. The right to optimum treatment
4. The right to know
5. The right to self determination
6. The right to privacy
7. The right to redress
8. The right to die in dignity
9. The right to moral and spiritual comfort

4.11 Feedback mechanisms as ways to ensure patients' right to participation.

In order to supplement the information gathered from the research on the Patients Right to participation, it also looked at the additional aspects regarding the existence and effectiveness of *feedback mechanisms at health facilities that could ensure effective patients' participation and therefore an improvement in the quality of health care delivery.*

Figure: 1 Patients' awareness of specific feedback mechanisms at health facilities %



Almost half of respondents are still not aware of feedback mechanisms at health facilities. Furthermore, from the figure above, we note that of the total number of people who are aware of the existence feedback mechanisms (, the majority mentioned a doctor or a nurse as the available feedback mechanism, rather than an intended avenue such as the suggestion box or complaints desk. This suggests they may assume the doctor or nurse is also there to receive feedback since they are the persons that the consumers come in contact with at the health facility.

With regards to the suggestion box, only 16% of the respondents mentioned it as a feedback avenue. Knowledge of a suggestion box was lower in Health Units surveyed in Masaka District.

4.12 Response to the complaints that are forwarded to the management of the health unit.

During the research, the questionnaire provided made a provision of getting feedback from the management of the health unit by patients once they have made a complaint as a way in which their participation can be ensured such that the quality of the health service delivery can be improved. It was found out that the majority of patients do fear even to make a complaint since they have a fear that once they complain, they will not receive the best treatment or even miss treatment.

Figure: 2 Responses given by the health unit to the patients' complaints? %

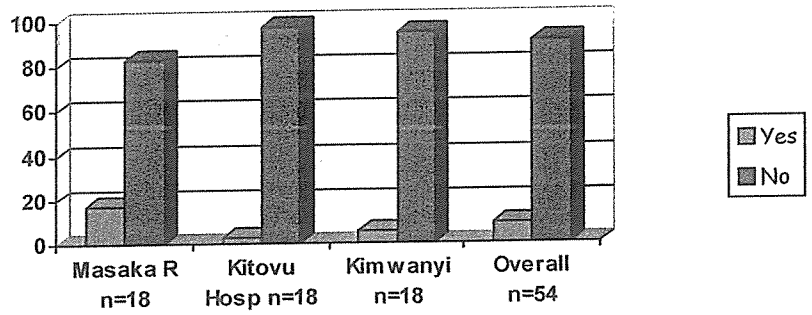


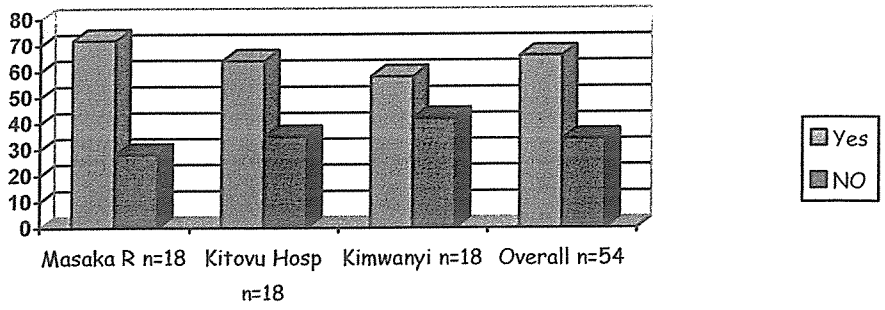
Figure indicates only 9% of total respondents stated that the health facility provides them with feedback on their complaints, with a higher proportion (17%) in Masaka Referal Hospital mainly due to the large number of patients they receive in a day.

The biggest number of respondents on how the feedback is given on their complaint indicated that in most cases changes are done, say for example if there has been a complaint on an inefficient health worker, at times this person is changed or at times suspended for a given period of time.

4.13 Problems that hinder patients participation.

As in any organization or setting, problems are expected to happen and this was not an exception in this kind of research whereby, patients indicated that they have a lot of problems that are a hindrance to their right of participation while seeking health services.

Figure: 3 Patients indicating hinderance to participation %



The basis for the problems that were encountered by the patients while trying to participate in the seeking of health services included the following:

Figure: 4 Reasons why patients do not participate.

i. Rude health providers
ii. Lack of provision of a mechanism for participation
iii. Lack of respect for patients
iv. Lack of knowledge of the availability of patients' right to participate

4.14 Interpretation of the right to participation.

Participation refers to the access patients have to be a part of health related affairs such as meetings, organisations, civil society groups or institutions. From this participation, patients can actively elect representatives who will then be able to access and influence government policy. An example of this type of participation can be found in the Community Based Organizations (CBO), which in many cases are in charge of the management of health units at the sub-county level. In addition. In this research, patients were asked if they know that they have the right to participate in any health related affairs.

Table: 4.14 'The Right to Participation in health affairs(%)

	Masaka Referal Hospital	Kitovu Hospital	Kimwanyi HC
Yes	20.5	38.3	35
No	68.7	45.7	55
Not sure	10.8	16	10
	100	100	100
Number	18	18	18

Source: Appendix A.

General results shows that almost patients do not recognise the right to participation. One out of every three provider expressed knowledge of the right. Participation in health related affairs do not depend on the level of awareness about the right.

Some of the participants explained their participation basing on the socio-econmic status of some of the patients. They thus noted that ***"Participation is most common, but not restricted to, in the middle-income and better-off socio-economic groups and for patients attending NGO and private clinics"***.

Although the focus groups engaged in livelier discussions, all groups had essentially the same or similar responses to the questions posed. They were able to mention some of the patients rights as show in the previous parts of the report, and provided significant input.

All participants had visited health facilities, but few were aware that encouraging the patient's right to participation in health can improve the quality of health services. All participants agreed that even the consumers who were aware of the right to participation were not inclined to use them. The reason given was fear of not receiving good service, especially if the participation was a complaint. They also agreed that, "society has gotten into a culture of not complaining".

These at the same time mentioned the Health Unit Management Committee (HUMC) and suggestion box, Hospital Hotline, patient – doctor meetings as available means to the observation of the right to participation at their health facilities. Unfortunately, they added that people were not sensitized about their right to participate and provide feedback and were hence, not using the available means.

CHAPTER FIVE

FINDINGS, RECOMMENDATION AND CONCLUSION

5.1 Summary of Findings

The overwhelmingly majority of surveyed respondents, FGD participants and health officials, agree that the right to participation is not only a consumer's right, but also essential in promoting and improving health care. Following is a summary of the major study findings:

- The majority of consumers surveyed, as well as focus group participants, were not aware of the patients' rights in general and in particular the right to participation while seeking health services as a means of improving the quality in the delivery of health services.
- About half (53%) of the consumers surveyed stated they were aware of the existence of feedback mechanisms at their health facility. The majority of consumers (89%) and providers (63%) however, mention the doctor or nurse as the feedback mechanism rather than the intended suggestion box or HUMC.
- Many providers report that even if the suggestion box is there, consumers do not use it and providers do not open it. Likewise, FGD participants stated that most people were not aware of the suggestion box. Hence this shows that there is a general lack of awareness of patients' right to participation.

- The highest percentage of patients' participation was found in NGO health facilities (76%), compared to 44% in government and 40% in private FP health facilities.
- FGD participants and health officials mentioned there was less awareness and availability of patients' right to participation in private-FP health facilities and in urban areas.
- A low 28% of surveyed consumers have ever provided feedback to health facilities. In contrast, 91% of surveyed providers state that consumers provide feedback. Although we were unable to confirm why consumers do not provide more feedback, focus group participants suggested many consumers may not provide feedback for fear of receiving poor service. This means that whether there is any satisfaction or not the patients just continue to receive what ever treatment is available.
- Consumers surveyed from NGO health facilities provide more feedback (43%) than government (23%) and private-FP (18%). This result suggests NGO health facilities may establish better relationships with health consumers. This is the major of patients' participation at the health facilities.
- Masaka Refferal Hospital had the lowest percentage of consumers who were aware of the existence of the patients' rights and more especially the patients' right to participation. This indicated that due to its being a public hospital, little or no attention is paid to improve the quality of health services delivered.

Overall, respondents from NGO health facilities stated to be more aware of feedback mechanism and the right to participation and hence provide more feedback to the health facilities than respondents from government and private-FP health facilities. Likewise, private-FP health facilities had the least consumer participation.

5.2 Recommendations

The following are a list of recommendations with regards to the introduction and/or improvement of feedback mechanisms at health facilities.

1. **There is a need to increase the level of awareness of the patients' rights in general and more especially the right to participation, since it is the basis upon which other rights are based.** MOH should ensure that a bill of rights is drafted and enforced to ensure that once community is participation, there will be improved delivery of services since they will take charge and will therefore be concerned with the general welfare of the health facilities.

2. **Health consumers and providers need to be sensitized that providing feedback regarding their health care is their right.** In addition, feedback will assist in the overall improvement of the functioning of the health facility, which will lead to better health care and health.

3. **The Health Unit Management needs direction and focus.** Members need proper training on their responsibilities and especially on how to handle suggestions and complaints, including how to inform consumers that feedback was addressed. Likewise, the HUMC could be in charge of opening the suggestion box and addressing the feedback on a timely basis. There should be monitoring systems in place to ensure that members are chosen from the community and that the committee is functioning properly. Follow up training is needed when new members are integrated. This would enforce participation hence the improvement in the quality of the health services delivered.

4. **NGOs, CBOs should become an integral part of the health system in Uganda.** That is to say, they should be involved in training workshops sponsored by the MOH. A perfect opportunity to initiate this would be to participate in the MOH training of *Village Health Teams* (VHT). These organizations could be responsible for modules dealing with patient's rights, including the right to provide feedback. They should work within the MOH framework, in order to create a larger impact their efforts to improve the quality in the delivery of health services.

5.3 Conclusion

Finally, in order to generate a sustained impact, patients' rights and in particular the right to participation are to be addressed and included in the planning component of the health facility. This will assist in promoting lasting collaboration between providers and consumers, which in turn leads to improved health care.

APPENDIX A

GENERAL QUESTIONAIRE

This questionnaire is put forward to you mainly for study purposes, and its main aim to find out how the right to participation can improve the quality of health services.

You are therefore kindly requested to fill in these questions, by ticking the boxes, which bear the answer of your own choice, and fill in the open questions with information required. There is no correct or wrong answer to these questions but it is a requirement of your opinion. Confidentiality will be observed to ensure that the information you have provided remains for academic purposes only.

Please answer the following

1. Age.....
   Sex.....
   Tribe.....
   Education.....
   Occupation.....

2. Mention some of the illnesses/injuries that are handled in this health facility
   .....
   .....
   .....

3. How do you rate the services that are provided in this health facility

I	Good	
II	Bad	
II	NOT SURE	

Give reasons for your answer

.....

.....

.....

4. Do you get enough time during consultation with the health worker?

I	YES	
II	NO	
II	NOT SURE	

5. Rate your relationship with the health workers in this health facility?

I	GOOD	
II	FAIR	
II	BAD	

Give a comment on your answer

.....

.....

.....

6. Do health workers communicate with you about your sickness and treatment?

I	GOOD	
II	FAIR	
II	BAD	

7. Have you ever heard of patients' rights?

I	YES	
II	NO	
II	NOT SURE	

If yes, mention some of the patients' rights you know.

.....

.....

.....

8. Some of the means used to ensure patients participation are; the suggestion box, complaints desk, availability of HOT LINES, and others. do you have any means/ways put in place in this health facility to ensure patients participation in all matters that concern their treatment?

I	YES	
II	NO	
II	NOT SURE	

If yes mention them

.....

.....

.....

9. Do you get any feedback/response towards your complaints from the management of this health facility?

I	YES	
II	NO	
II	NOT SURE	

If yes, how it done

.....

.....

.....

10. Are there any problems that hinder the patient's right to participation?

I	YES	
II	NO	
II	NOT SURE	

If yes, what is the basis for these problems?

.....

.....

.....

11. Do patients at this health facility know that they have a right to participate in all matters concerning their health?

I	YES	
II	NO	
II	NOT SURE	

Give reasons for your answer

.....

.....

.....

12. Do the patients in this health facility at times exercise any of their rights?

I	YES	
II	NO	
II	NOT SURE	

If yes, how is this done or ensured

.....

.....

.....

13. Are the patients satisfied with the health services they receive?

I	YES	
II	NO	
II	NOT SURE	

14. Suggest measures that can be taken to improve on the right to participation at health facilities and patients rights in general.

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APPENDIX B

INTERVIEW GUIDE - PATIENTS' RIGHT TO PARTICIPATION

1. Are you aware that patients do have rights while seeking health services?

2. What are some of these rights?

3. Do you think that patients' are aware of their health rights?

I	YES	
II	NO	
II	NOT SURE	

4. Have you ever made an attempt to observe these rights?

I	YES	
II	NO	
II	NOT SURE	

5. What mechanisms have been put in place to ensure that these rights are emphasized in the health facilities?

6. What kind of participation is allowed to patients while seeking health care?

7. What do you think would be the likely exemptions to the patients' right to participation?

8. What measures should be taken to improve the patients' right to participation at health facilities?

APPENDIX C

QUESTIONS – FOCUS GROUP DISCUSSION

1. Mention some of the patients' rights

2. Do you really feel that by encouring patients' participation in health will improve the quality of health services? Give reasons for your answer.

3. Suggest ways in which the observation of the patients' right to participation at health facilities can be ensured.