Uganda National Health Users'/Consumers' Organization (UNHCO)

Survey to Establish the General Level of Awareness about Patients' Rights

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Executive Summary

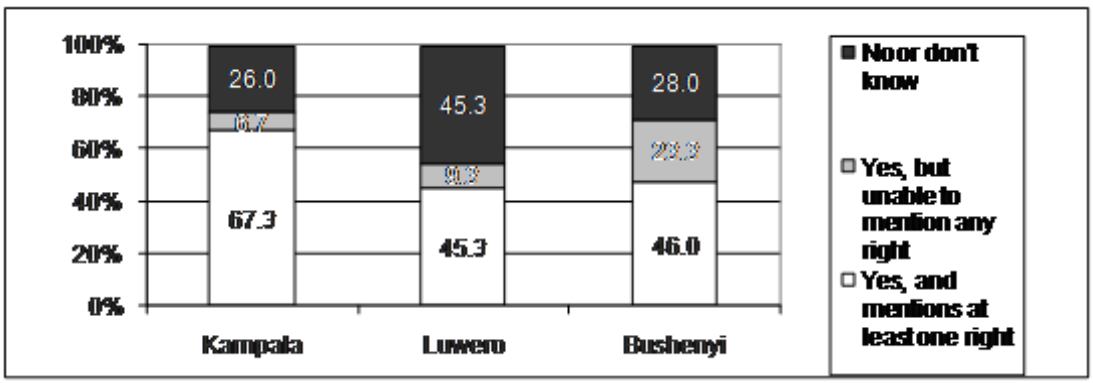
1. Background

The UNHCO Baseline survey was carried out in Kampala, Luwero Town Council and Bushenyi Town Council in May 2002. 450 patients were interviewed at 18 different health units immediately after receiving treatment. Eighteen health care providers were also interviewed to enable triangulation. The main objective of the Baseline Survey was to examine whether patient's rights are being respected in practice and to establish the general level of awareness about patient's rights.

2. Awareness of patient's rights

Around half of the patients interviewed in each survey area claimed that patients have rights and were able to mention at least one of the ten patient's rights (figure S.1 refers). Patients in Kampala were most aware of rights. Men are significantly more aware of their rights than women. Rights awareness was also found to correlate with socio-economic status. In Kampala and Bushenyi, the better-off patients are significantly more aware of their rights than poor people. The level of rights awareness did not vary systematically by the type of health unit visited (government, NGO and private-for profit). In comparison, *all* of the interviewed health providers acknowledged that patients have certain rights. When asked, each of them could mention at least four of the ten patient's rights.

Figure S.1 Do patients have rights? Patient's response by survey area



Source: Appendix A.1.

Table S.1 Awareness of each of the ten patient's rights

	Health providers	Patients		
		Kampala	Luwero	Bushenyi
Optimum treatment	46	45	30	31
Self-determination	50	19	13	7
Privacy	62	15	5	13
Individual respect	55	11	5	8
Equal treatment	45	9	6	4
Participation and representation	34	7	1	0
Right to know	55	5	7	2
Redress	28	3	1	0

Die in dignity	22	1	0	0
Spiritual and moral comfort	28	1	3	0

Patients were most familiar with the following 4 rights: *Optimum treatment, self-determination, privacy and individual respect.* In contrast, almost none of them mentioned *the right to spiritual and moral comfort, to die in dignity, and redress.* This pattern was broadly similar for health care providers, although the level of awareness was substantially higher (table S.1 refers).

3. Are patient's rights respected?

The 2002 UNHCO Baseline Survey also examined whether measurable aspects of patient's rights are respected in practice. The major findings emerge as follows:

The right to individual respect was measured by examining whether the health worker made any inappropriate comments about the personal appearance of the patient. It was found that female patients were more likely to receive such comments than their male counterparts, especially in Kampala. A majority of these comments were considered inappropriate, such as comments about personal looks. Thus, the survey found a number of cases where the right to individual respect was violated. Lack of understanding of the health worker about which comments were appropriate is a possible explanation.

The right to receive equal treatment was examined by asking patients whether they experienced differential treatment in general, and, more specifically, whether the order of the queue was respected. Almost all patients felt that they were treated equally, although one in ten felt that the order of the queue was not respected. These patients were primarily from government and NGO health units. There was no systematic bias against vulnerable groups, such as poor people or women.

The right to optimum treatment was interpreted by investigating whether malaria patients received a blood test during the course of treatment. Malaria was the most frequent cause of illness in Bushenyi (54% of all patients), but almost half of the malaria patients there were never tested. A majority of these patients were women typically treated in a government health unit, which did not have the necessary resources to perform a blood test, according to the health providers. The patients, however, were unaware of why they were never tested.

Patients are generally unaware of **the right to know**, and as a consequence this right is frequently being violated. A majority of patients are never told about the kind of illness they suffer from, the cause of this illness, the side effects of medication prescribed nor the cost before treatment. In contrast, more than half of the health providers are aware of the right, and although they claim to respect it in practice, the evidence from patients reveal that this is not the case.

The right to self-determination was measured by asking patients and health providers whether alternative medication is offered and whether the patients have a say in the choice of medication. The survey reveals that patients are unlikely to be offered alternative medication, especially poor patients. Furthermore, few patients, especially female, feel that they actually have a say in the choice of medication. This right is therefore not respected in practice. In comparison, almost all health care providers claimed that they offer alternative medication for the same illness, and half of them claimed that patients have a choice.

The right to privacy is generally respected, if measured by asking patients whether they were comfortable with the persons present in the examination room. There were, nevertheless, 16 patients who did not feel comfortable, of which 13 were women, thus revealing a gender bias.

The right to participation was examined by asking patients whether they participate in health organisations or groups. The organisation rate was estimated at 7% which compares well with national data for urban Uganda on women's groups (6%), saving's groups (6%) and professional organisations (1%). The poor are slightly less likely to be organised compared with the middle-income and better-off groups.

Patients are generally not aware of where they can complain about the health services received. This makes it difficult in practice for them to exorcise **the right to redress**. The poor patients were least aware of where to complain. According to health providers, it was quite common that patients complain to the management of the health unit.

The right to die in dignity was examined by asking respondents when the treatment of a terminally ill patient should stop. Despite the complexity of this question, most respondents showed signs of understanding it. Patient's answers were a combination of ethical and pragmatic considerations. Middle-income groups were more likely to let the family decide, while all respondents in Kampala and the better-off in Bushenyi stressed that treatment should stop when the patient can no longer afford the treatment.

Finally, **the right to spiritual and moral comfort** was approached by asking respondents about who should decide on the spiritual and moral comfort that a patient could access when admitted to a health unit. Both patients and providers were in agreement that the decision should be with the individual, although some also mentioned the family. Men were more likely to say individual, while women mentioned family more often.

4. Some aspects of the quality of health care

In addition to information about rights, the 2002 UNHCO Baseline Survey also measured a few aspects related to the quality of health care. These findings are briefly summarised below:

- A majority of the interviewed patients wait for less than 10 minutes before receiving treatment. Less than a third of them wait for more than half an hour. Patients in government health units have the longest waiting periods.
- A consultation typically takes less than 20 minutes.
- Trust in health worker was almost universal amongst patients in Kampala and Bushenyi, while 17% in Luwero expressed signs of lack of trust. The problem in Luwero was related to Kasana Health Centre IV, which is a government health unit. Reportedly, the staff feared the interviewer and for good reasons: one of the doctors was drunk on duty.
- Satisfaction rates were generally high amongst patients, especially in private health units. This, however, should be compared with the relatively low expectations that patients have about the treatment and their lack of knowledge about patient's rights. As this report demonstrates, these rights are frequently violated and if patients were aware of their rights, the satisfaction rates would, arguably, be much lower.

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Acronyms and Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
BUSH	Bushenyi Town Council
CC	City Council
CBO	Community Based Organisation
FP	For Profit
GoU	Government of Uganda
HC	Health Center
HIV	Human Immunodeficiency Virus
KLA	Kampala City Council
LUW	Luwero Town Council
MFPED	Ministry of Finance, Planning and Economic Development
MOH	Ministry of Health
NGO	Non Governmental Organization
NRF	National Referral Hospital
TC	Town Council
UBOS	Uganda Bureau of Statistics
UDHS	Uganda Demographic and Health Survey
UNHCO	Uganda National Health Users/Consumers Organisation
UNHS	Uganda's National Household Survey
UPPAP	Uganda Participatory Poverty Assessment Process
UTL	Uganda Telecom Limited

Chapter 1. Introduction

1.1 Background

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.

Patient at Nsambya Hospital, Kampala.

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 optimum treatment was violated, and this despite the fact that she was delivering at an NGO Hospital in Kampala, where she paid for the health service.

Uganda National Health Users/Consumers Organization (UNHCO) has worked in Uganda for around one year trying to address the issue of patient's rights. So far, the Organization has relied on anecdotal evidence, such as that presented above, to make their case heard amongst the public in general and the health sector in particular.

Although anecdotal evidence can be compelling, it is often difficult to assess the prevalence of the situations being described. In recognition of this, UNHCO decided to commission a baseline survey in order to get quantitative information about general awareness about patient's rights in Uganda and the extent to which such rights are being violated.

The 2002 UNHCO Baseline Survey covered Kampala City Council, Luwero Town Council and Bushenyi Town Council. It is hoped that the results presented in this report can become a useful tool in the implementation actions to empower patients and improve the quality of health care in Uganda.

Box 1. The ten patient's rights

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 participation and representation
8. The right to redress
9. The right to die in dignity
10. The right to moral and spiritual comfort

Source: UNHCO (2002).

1.2 Objectives of the Survey

The 2002 UNHCO Baseline survey was designed to provide information about the quality of health care treatment in urban Uganda with particular reference to health consumers' rights. The specific objectives of the 2002 UNHCO Baseline survey are:

1. To establish the level of awareness about patient's rights amongst health users and health providers.
2. To examine whether patient's rights are being respected in practice.
3. To inform the new Information, Education and Communication Strategy to be developed by UNHCO.
4. To inform development partners and policy makers about the current situation of patient's rights in Uganda.

The survey was designed to examine whether health care practice and the level of awareness varies by different background characteristics of the patient, such as gender, socio-economic status of the patient or type of health care provider.

The basic idea of the baseline survey is that it is the first in a series of surveys attempting to establish trends in the quality of health care and awareness about patient's rights in Uganda.

1.3 Organisation of the Survey

1.3.1. Sample Design and Implementation

Coverage

The survey covered the urban areas of Kampala, Luwero and Bushenyi Districts. More specifically, the survey sampled health units within Kampala City Council, Luwero Town Council and Bushenyi Town Council.

Approach

Given the budget and time constraints of the survey, 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. Enumerators were instructed to interview respondents as these were leaving the health unit. 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 18 different health units in the 3 survey areas through random sampling. The randomness of the sample is critical to ensuring that the sample adequately describes the characteristics of the urban population. 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.

The survey administered two different questionnaires: A *Health User Questionnaire* and a *Health Provider Questionnaire*. 446 interviews were conducted with health users (patients) – around 150 interviews in each of the three different locations. The survey also aimed at interviewing one staff member from each of the 18 sampled health units. Patients were interviewed at the clinic were they received treatment, and this allowed direct triangulation with the answers from the health care providers.

An interview with patients and health providers lasted, on average, 15 minutes. In the beginning of the interview, enumerators made an introductory statement to clear the ground for the interview and indicate that the data sought from the respondent would be handled with confidentiality and used only for the purposes of the study. At the end of the interview the respondent, whether patient or health provider was given a UNHCO brochure explaining in more detail the 10 patients' rights.

Time

The fieldwork for the survey was undertaken in May 2002. Data entry and analysis was done in May and June 2002.

Selection of Health Units

The selection of health units was guided by the following documents:

1. Ministry of Health, 2001b, *Financial Year 2001/02 District Transfers for Health Services*, Kampala.
2. Ministry of Health, 2000, *Inventory of Health Institutions in Uganda,* Kampala.
3. Uganda Telecom Limited (UTL), 2000/01, *Uganda Telephone Directory*, Kampala.

(1) Contains a list of all NGO health units in Uganda which receive GoU funding. (2) contains a list of all the different types of health units in each Health Sub-county in Uganda. (3) was used to identify the private health units in Kampala.

The health units were selected according to the following 3 strata:

1. Type of provider (Government, NGO and Private-for-profit).
2. Size of health unit (Big or small).
3. Health Sub-county.

Kampala C. C.: Sample Design

Kampala was the biggest sample area with an estimated population of 902,900 in 2000 (UBOS, 2000). Given the identified strata, the following sampling procedure was adopted using a combination of selective and random sampling:

1. Mulago Hospital was chosen because it is a National Referral Hospital (NRF).

2. Nsambya Hospital was chosen to represent a big NGO Hospital.

3. International Hospital was chosen to represent a big private Hospital.

4. A small private health unit was then to be selected. Most private health units listed in the telephone directory appeared to be located in Kampala Central Sub-county. Since International Hospital is also located in the same Health Sub-county, it was decided to sample the small private health unit in the periphery of Kampala. 3 non-central clinics were identified from the telephone directory:
    a. Biva Maternity and Health Clinic (Rubaga Rd.);
    b. Eureka Medical Services (Gaba Town) and;
    c. St. Francis Clinic (Kireka).

    A dice was thrown to simulate a random sampling and St. Francis was selected.
5. To select a small NGO unit, the team used MoH (2001b). The substantial health care providers were located in Kampala Central (Adventist M. C. and St. Johns). St. Johns was selected through random sampling.

6. Rubaga Health Sub-county was not represented in the sample, and the small GoU provider was therefore selected from there. From MoH (2000), three substantial providers were identified:
    a. Kisenyi (Rubaga North);
    b. Kawala (Rubaga South) and;
    c. Wankulukuku (Rubaga South).

    The latter was selected randomly.

The sample design (illustrated in table 1.1.a) represents 6 of the 8 Health Sub-counties in Kampala. The sample size was 33 for big health units and 17 for small health units, reflecting the fact that bigger health units have more patients than small.

Table 1.1.a. Sample Design, Kampala.

Health unit	Type of provider	Size of health unit	Health Sub-county	Sample
Mulago Hospital	Government	Big (NRH)	Kawempe South	33
Wankulukuku	Government	Small	Rubaga South	17
Nsambya	NGO	Big (HC IV)	Makindye West	33
St. Johns	NGO	Small	Kampala Central	17
International Hospital	Private FP	Big	Kampala Central	33
St. Francis	Private FP	Small	Nakawa	17
Total				**150**

Kampala C. C.: Sample implementation

The enumerators faced significant problems in implementing the Kampala sample as discussed below:

1. It was not possible to get the consent of Nsambya Hospital to conduct the survey at their premises, despite the fact that written permission from Kampala City Council had been granted. The enumerator decided to interview patients outside the premises of the hospital (close to the entrance), but was chased away by the staff who threatened to report him to the police. Nevertheless, the enumerator managed to interview 9 patients, whose responses were retained in the final sample. Kibuli Hospital was selected to replace Nsambya Hospital and the interviewer faced no problems (the staff was very welcoming). 24 interviews were conducted there.

2. Despite the fact that St. John's Clinic appears on the Ministry of Health list as an NGO health unit receiving funding, the health unit does not exist. Adventist Medical Centre was selected to replace it, but the full sample of 17 interviews could not be implemented because there were too few patients. After two days, only 11 interviews were conducted.

3. It was not possible to conduct interviews at St. Francis health unit, basically because there were no patients or the patients were mainly children. This was a general problem for small, private health units, and the enumerator was therefore instructed to go to a clinic of his own choice, where there would be sufficient patients. 4-5 different private health units were contacted, and finally, Abbi Clinic (Bombo Rd.) was selected and 21 interviews conducted (rather than 17) to compensate for the fewer interviews conducted in small NGO health clinics.

The implemented sample (see table 1.1.b) covers 5 out of 8 Health Sub-counties in Kampala. The total sample was 150 – of these 50 interviews were conducted in Government health units, 45 in NGO health units and 55 in private clinics. 100 interviews were conducted in large health units, while 49 were conducted in small health units.

In terms of health providers, the survey team managed to interview one provider in Wankulukuku, Adventist and International Hospital, as intended. Two providers were interviewed in Mulago and Kibuli Hospitals, to compensate for the lack of an interview at Nsambya hospital. No interview was conducted at Abii Clinic. A total of seven health provider interviews were successfully completed.

Table 1.1.b Sample Implementation, Kampala

Health unit	Type of provider	Size of health unit	Health Sub-county	Sample
Mulago Hospital	Government	Big (NRH)	Kawempe South	33
Wankulukuku	Government	Small	Rubaga South	17
Nsambya	NGO	Big (HC IV)	Makindye West	9
Kibuli Hospital	NGO	Big (HC IV)	Makindye East	25
Adventist M. C.	NGO	Small	Kampala Central	11
International Hospital	Private FP	Big	Kampala Central	34
Abii Clinic	Private FP	Small	Kampala Central	21
Total				**150**

Bushenyi T. C.: Sample design and implementation

Bushenyi T.C. has an estimated population of 19,205 people in 2000[1]. Due to lack of a priori information about private health units in Bushenyi T.C., the sample was designed in co-operation between the team leader (situated in Kampala) and the supervisor (situated in Bushenyi). As a consequence, the distinction between sample design and implementation could not be maintained. The final sample implementation became an iterative process between what was intended and what was possible. The main constraint in this aspect was the lack of patients in small, private health units.

Table 1.2 summarises the final sample in Bushenyi. A total of 146 interviews were conducted, of which 49 were in Government-owned units, 50 in NGO clinics and 47 in private-for-profit health units. A substantial part of the sample (128) had to be collected in big health units due to the lack of patients in small units (18).

Table 1.2 Sample Implementation, Bushenyi T. C.

Health unit	Type of provider	Size of health unit	Health Sub-county	Sample
Bushenyi Health Centre	Government	Big (HC IV)	Igara East	49
Ishaka Adventist Hospital	NGO	Big (HC IV)	Igara East	50
Kyeizooba Farmer's H.C.	Private FP	Small (HC III)	Igara East	18
Bushenyi Medical Centre	Private FP	Big	Igara East	29
Total				**146**

The sample for the health providers went as planned (one interview per unit), although two interviews were conducted at Bushenyi Medical Centre to compensate for the missing interview at Abbi Clinic in Kampala.

[1] Own calculations based on UBOS (2000) and information from Ministry of Local Government. The population of Bushenyi Town Council is assumed to have grown at the same rate as Bushenyi District between 1991and 2000.

Luwero T. C.: Sample design and implementation

Luwero T.C. had an estimated population of 16,312 people in 2000[2]. The sampling procedure in Luwero T.C. was similar to that of Bushenyi T.C. in that the design could not be properly planned from Kampala due to lack of information about private health units. Again, it proved very difficult to conduct sufficient interviews in small, private units. Furthermore, it was difficult to reach the desired sample of 150, and it was consequently decided to move beyond Luwero T.C. and conduct 37 interviews in Nakaseke Health Sub-county.

The final sample in Luwero T. C. is summarised in table 1.3. The total sample of 150 was distributed as follows: Government (50), NGO (67) and Private-for-profit (33). A total of 63 interviews were conducted in big health units versus 87 interviews in small health units.

Again, the interviews of health providers went as planned. One interview was conducted in each of the health units with the exception of St. Joseph Medical Centre where no provider was interviewed due to the fact that only 3 patients had been interviewed there.

Table 1.3 Sample Implementation, Luwero T. C.

Health unit	Type of provider	Size of health unit	Health Sub-county	Sample
Kasana Health Centre	Government	Big (HC IV)	Katikamu North	50
Bishop Ceasar	NGO	Small	Katikamu North	15
Kasaala Health Centre	NGO	Small (HC III)	Katikamu North	15
Kiwoko Hospital	NGO	Big	Nakaseke	37
Patient's Clinic	Private FP	Small	Katikamu North	15
Hope Medical Centre	Private FP	Small	Katikamu North	15
St. Joseph M.C.	Private FP	Small	Katikamu North	3
Total				**150**

1.3.2 Questionnaires

As mentioned earlier, this survey administered a Health User Questionnaire, where the respondent is a patient, and a Health Provider Questionnaire, where the respondent is a health worker (typically a doctor or a nurse). The questionnaires are reproduced in Appendix D.

The Health User Questionnaire has 4 sections (A - D). Section A contains information about the respondent and where he or she lives. Section B are socio-economic questions. Section C contains specific questions about health care and rights. Finally, section D contains general questions about health care and patient's rights.

The Health Unit Questionnaire has 3 sections (A - C). Section A contains information about the Health Unit (name and type). Section B has questions related to the service delivery of the Health Unit. Section C contains general questions about health care and patient's rights.

[2] Calculated under the same assumptions as footnote 2.

The questionnaires were translated into the relevant local language (Luganda for Kampala and Luwero and Runyankole for Bushenyi. Interviews were conducted in the language which the respondent was most familiar with.

1.3.3 Training

The survey team consisted of the following members: 1 Team Leader, 1 Project Manager, 1 Supervisor / Enumerator, and 3 Enumerators. A half-day training for the enumerators was conducted on 4 May 2002. The training was conducted by the Team Leader (*Lars Moller*) and the Project Manager (*Karla Rivera*). The training explained the objectives of the survey and gave special attention to introducing the idea of patient's rights to the enumerators. The enumerators were also trained in conducting the interview in the intended manner and detailed instructions were given.

1.3.4 Data Processing

Filled questionnaires were carefully scrutinised for errors and inconsistencies before data entry. This happened on the same day as the interviews were conducted and was done by the Team Leader and Project Manager in Kampala and by the Supervisor in Bushenyi and Luwero. The questionnaires were reviewed to ensure that all questions had been answered, that the answers were readable and that there were no immediate inconsistencies in the answers. In the rare cases where information was missing, additional information was sought from the enumerators.

Enumerators were instructed to write down additional qualitative information based on statements from the patients on the back of the questionnaire. This information has been used to derive the 'voices of patients', which feature in this report.

Data entry was done by the Project Manager using Microsoft Access. Ranges of consistency checks were included in the data entry program. Once the data was entered it was 'cleaned' by the Team Leader using the statistical package, SAS. SAS was also used to generate the descriptive statistics presented in the report and to calculate the poverty models discussed in the subsequent sub-section. The data was entered into Microsoft Excel for presentational purposes.

1.3.5 Poverty Analysis

An interesting aspect of the survey was whether the answers of the respondents depended on their socio-economic status or level of poverty. To assess this, a reliable measure of poverty was constructed using poverty correlates. The idea behind the use of poverty correlates is briefly explained as follows:

It is currently estimated that 35% of the Ugandan population live below the poverty line. Poverty is higher in the rural areas, where 39% are poor, compared to the urban areas where only 10% are poor. In fact, 96% of the poor population live in the rural areas (MFPED, 2001a). The measure used by Government to estimate poverty is household consumption per adult equivalent. If a household consumes less than a certain minimum then the household members are considered to be poor. To estimate household consumption, Government relies on household surveys conducted by Uganda Bureau of Statistics. This survey has very detailed questions about how much the household has spent on more than 200 different consumer goods in a given time period.

It would be impossible to repeat such a survey in a small study like the 2002 UNHCO Baseline Survey, but fortunately there are reliable shortcuts. The answer is to use poverty correlates. A poverty correlate is a poverty indicator that has a high level of statistical correlation with household consumption. In a study conducted by Ministry of Finance, Planning and Economic Development (2001b), the best poverty correlates for urban Uganda were identified as illustrated in table 1.4.

Table 1.4 Best 15 Poverty Indicators in Urban Uganda

1. Number of children (below 15 years) in the household
2. Whether the household head has a spouse
3. Years of education of the spouse
4. Years of education of the best education household member
5. Whether the household had bought petrol
6. Household expenditure on soap
7. Household expenditure on toothpaste
8. Household expenditure on transport
9. Asset score
10. Members per room
11. Type of floor
12. Type of cooking fuel
13. Type of drinking water source
14. Whether each member has a blanket
15. Whether the household members ate meat last week

Source: MFPED (2001b).

Based on these 15 variables in the UNHS (1999/2000) household survey, a multivariable regression model can be constructed to predict household expenditure per adult equivalent (the poverty measure). If the urban population in Kampala is divided into three equally big groups (terciles): Poor, Middle income, and Better-off, then this statistical model will correctly classify two-thirds of the households. The associated error margin occurs, because the model predicts a household to be in the 'neighbouring' category, i.e. the household is in fact poor, but is predicted as being in the middle-income group. In only 2% of the cases will the model predict a poor household to be better-off, and vice versa.

If one is willing to accept this error margin (that the model is wrong in 1 out of 3 cases, but almost never totally wrong) then it is possible to construct a useful measure of socio-economic status on the basis of these indicators. In the context of the 2002 UNHCO Baseline Survey, this measure can then be used to examine whether the treatment of the patient and the knowledge of their rights correlate with his or her socio-economic status.

To keep the interview relatively short and reduce the number of questions necessary to generate the poverty measure, it was decided that a poverty correlates model should be developed drawing upon a maximum of 6 variables. Reducing the model from 15 to 6 variables, obviously increases the error margin, but not as much as one would expect. The following variables were used in the 2002 UNHCO Baseline Survey:

Table 1.5 Best 6 Poverty Indicators for Urban Uganda used in 2002 UNHCO Survey

1. The number of household members per room
2. Household expenditure on bathing soap and washing soap
3. Household expenditure on meat
4. The number of years of education of the household head
5. Type of cooking fuel
6. Type of floor

Source: Author's own calculations based on models developed for MFPED (2001b).

Fortunately, this only reduces the predictive capability from 66% in the 15 variable model to 64% in the 6 variable model. One reason for this is that the 15 variable model is a linear model, while the 6 variable model allows for non-linear expressions. The UNHCO questionnaire was therefore designed to capture information on the 6 variables listed above. A SAS programme was developed to estimate the predicted consumption of the households of each of the respondents. A detailed summary of the two models is presented in appendix C.

Due to lack of information about the correct level of household consumption, it was not possible to examine the extent to which the model predicted correctly in practice. The error margins illustrated above were calculated using the actual level of household consumption of the households in the UNHS (1999/00) survey, conducted by UBOS, and comparing them with the predicted level of consumption based on the poverty correlates.

There are, however, other tests that can demonstrate whether the model worked well in the UNHCO survey. One such test is to compare the distribution of the predicted consumption measure calculated on the basis of UNHCO data with the actual consumption distribution in the UNHS survey for the same geographical area. Table 1.6 below makes this comparison between the predicted consumption for Kampala respondents in the 2002 UNHCO Baseline Survey and the actual household consumption for Kampala district according to the UNHS (1999/00) survey. The results are striking and positive: The predicted average consumption in the UNHCO survey is remarkably similar to that of the UNHS, as are the tercile cut-off points.

Table 1.6 Comparative Statistics of the Poverty Measure for Kampala District

Survey	Average	1. Tercile Cut-off point	2. Tercile Cut-off point
UNHCO (predicted)	10.07	9.87	10.27
UNHS (actual)	9.94	9.60	10.13

Note: The figures are expressed as the natural logarithm of household expenditure per adult equivalent in 1993/94 Ugandan Shilling.
Source: Own calculations based on data set from MFPED (2001b).

Finally, it is stressed that the 2002 UNHCO Baseline Survey applied the socio-economic variable using relative rather than absolute values. Consequently, the poorest group in Kampala is different from the poorest group in Luwero and Bushenyi. Since the income level in Kampala is higher than in the other two locations, the poorest group in Kampala is better off than the two others. Had an absolute approach been chosen, this would have resulted in very small sample sizes for some of the socio-economic groups in certain areas.

Chapter 2. Respondent Characteristics

This chapter presents information on the demographic and socio-economic characteristics of the respondents (health users) that were interviewed in the survey, such as age, sex, educational attainment, household expenditures and some dwelling characteristics. The reported type of illness is also presented. Where possible, the sample characteristics are compared with nationally representative data for urban Uganda to identify possible biases in the sample. Preferably, the sample distribution of the present survey should be comparable to the distribution for urban areas in national surveys, such as the Uganda National Household Survey (UNHS 1999/2000) and the Uganda Demographic and Health Survey (2000/01), both conducted by Uganda Bureau of Statistics.

2.1 Sex of respondents

In Kampala, an almost equal proportion of men and women were interviewed. This was not the case in Luwero and Bushenyi, where more women than men were sampled.

Table 2.1 Sex of respondent (percent distribution)

Sex	Kampala	Luwero	Bushenyi	Uganda (urban)
Male	48.7	36.0	43.8	47.5
Female	51.3	64.0	56.2	52.5
Total	100.0	100.0	100.0	100.0
Number	150	150	146	-

Note: The figures for urban Uganda, extracted from UDHS (2000/01), are shown for comparison only. These figures should not be confused with an average of the three areas covered in the 2002 UNHCO Baseline Survey.
Source: UNHCO (2002) and UDHS (2000/01).

2.2 Age of respondents

The age distribution of the respondents in the UNHCO survey is comparable to that of urban Uganda (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 2.2 Age of respondent (percent distribution)

Age group	Kampala	Luwero	Bushenyi	Uganda (urban)
15-30 years	66.0	53.3	55.5	61.6
31-45 years	22.7	28.0	33.6	26.3
46+	11.3	18.7	11.0	12.1
Total	100.0	100.0	100.0	100.0
Number	150	150	146	-

Note: The national data only refers to the population aged 15 years and above.
Source: UNHCO (2002) and UDHS (2000/01).

2.3 Educational level of respondents and household heads

The educational distribution of the sample is also broadly similar to that of urban Uganda. Where differences occur, these can be explained by the fact that the population in Kampala is relatively better educated that the population in Luwero and Bushenyi. The proportion of respondents who have no education is the lowest in all three areas. There are relatively more respondents in Kampala with secondary or higher education compared to the two other areas.

Table 2.3.a Educational level of respondent (percent distribution)

Level of education	Kampala	Luwero	Bushenyi	Uganda (urban)
No education	4.0	22.7	18.5	7.4
Primary education	26.0	53.3	46.6	44.7
Secondary education+	70.0	24.0	34.9	47.9
Total	100.0	100.0	100.0	100.0
Number	150	150	146	-

Source: UDHS (2000/01).

Respondents, who did not consider themselves as household heads, were also asked about the educational level of the household head. As expected, the educational attainment of the head is generally higher than that of the respondent (table 2.3.b refers).

Table 2.3.b Educational level of household head (percent distribution)

Level of education	Kampala	Luwero	Bushenyi	Uganda (urban)
No education	10.7	23.3	19.2	7.4
Primary education	18.7	46.0	40.4	44.7
Secondary education+	70.7	30.7	40.4	47.9
Total	100.0	100.0	100.0	100.0
Number	150	150	146	-

Source: UDHS (2000/01).

2.4 Dwelling characteristics

Respondents were also asked questions about their dwelling. It was not possible for the enumerators to physically verify this information because the interview did not take place in the household.

There are substantial differences in the type of floor by survey area. In Kampala, cement floors are predominant, while earth or cow dung is the norm in Bushenyi. Luwero falls somewhere in between with about half of the respondents having a floor made of earth or cow dung and the other half having a cement floor.

Table 2.4.a Type of floor (percent distribution)

Type of floor	Kampala	Luwero	Bushenyi	Uganda (urban)
Earth / Earth and Cow dung	4.0	56.7	80.8	28
Cement	92.7	42.7	18.5	72
Other	3.3	0.7	0.7	0
Total	100.1	100.1	100.0	100
Number	150	150	146	-

Source: UBOS (2001).

Because of these differences, it is very difficult to compare the sample distribution with the national distribution for urban areas. However, the differences observed in table 2.4.a appear intuitive when the level of urban development and distance to Kampala are taken into consideration.

There are also substantial differences in the type of cooking fuel used by survey area. In Kampala, charcoal is most frequently used, but firewood, electricity and paraffin are also relatively common. In contrast, in Luwero and Bushenyi, firewood and charcoal are the only types of cooking fuel, with firewood being almost universal in Bushenyi.

Table 2.4.b Type of cooking fuel (percent distribution)

Type of cooking fuel	Kampala	Luwero	Bushenyi	Uganda (urban)
Firewood	9.3	72.0	96.6	20
Charcoal	75.3	28.0	2.7	70
Paraffin	4.0	0.0	0.7	5
Electricity	8.0	0.0	0.0	3
Other	3.3	0.0	0.0	2
Total	100.0	100.0	100.0	100

Source: UBOS (2001).

Another indicator of household well-being is how crowded the household members live (members per room). In Kampala and Luwero, on average, around 2 persons live in each room. This figure is lower in Bushenyi with only around 1.5 persons per room, on average. The Bushenyi estimate is comparable to national data for the Western region, which estimates 1.88 members per room (not illustrated), which is much lower than in the rest of Uganda. The sample distribution is broadly similar to that of urban Uganda.

Table 2.4.c Number of members, rooms and members per room (percent distribution)

Variable	Kampala	Luwero	Bushenyi	Uganda (urban)
Household members	5.43	4.81	5.27	4.62
Rooms in dwelling	3.38	2.62	3.79	-
Members per room	2.07	2.15	1.45	2.46

Source: UNHS (1999/2000).

2.5 Selected household expenditures

Information on household expenditure was also captured by the survey. Respondents were asked how much money they had spend on bathing soap and washing soap over the last 30 days. Households in Kampala reported soap expenditures which, on average, were twice as high as in Luwero and Bushenyi. A question was also asked about how much the household had spent on meat during the last 7 days. Again, the level of expenditure was highest in Kampala. In fact, it was twice as high as in Luwero and three times higher than in Bushenyi.

Table 2.5 Average household expenditures (Shillings)

	Kampala	Luwero	Bushenyi
Soap (last 30 days)	5,044	2,725	2,308
Meat (last 7 days)	8,077	3,199	2,260

2.6 Type of illness of respondent

Finally, respondents indicated the type of illness/injury that they had been treated for. Not surprisingly, malaria/fever was the illness most frequently reported. This illness accounted for one third of the illnesses in Kampala and Luwero, and more than half of the illnesses in Bushenyi. To compare with national data, malaria contributed to more than a third of the proportional morbidity registered in Government health clinics (Ministry of Health, 2001a). It is also perceived, that malaria is on the increase in the Western region, explaining the statistics in Bushenyi (see for instance MFPED, 2002).

Respiratory illnesses and accidents were also important, but to a lesser extent than malaria/fever. There were a large proportion of respondents (more than a third) who did not have an illness identified in the questionnaire. (The options in the questionnaire were identical to those listed in the UNHS (1999/2000) Socio-economic Questionnaire). This information was, however, captured during the interview. The most typical illness/injury mentioned amongst those who answered 'other' was pregnancy related (24 cases). More than 30 other types of illnesses were mentioned, but none of these illnesses were particularly frequent.

Table 2.6 Type of illness/injury (percent distribution)

Type of illness/injury	Kampala	Luwero	Bushenyi
Malaria/fever	34	32.0	54.1
Diarrhoea	1.3	3.3	1.4
Accident	6.7	2.0	6.2
Measles	0.7	0.7	0.0
AIDS	1.3	2.0	0.0
Dental	2.7	0.7	5.5
Respiratory	6	8.0	0.0
Intestal infections	5.3	4.7	3.4
Skin infections	4.7	1.3	1.3
Hyper tension	2	2.7	2.7
Ulcers	5.3	0.7	0.7
Other	30	42.0	42.0
Total	100	100.0	100.0
Number	150	150	146

Source: UBOS (2001).

In conclusion, the total sample compares very well with the data for urban areas collected in the 1999/2000 UNHS and in the 2000/01 UDHS. This confirms the reliability of the UNHCO data.

Chapter 3. Major Survey Findings

3.0 Rights Awareness

3.0.1 Survey approach

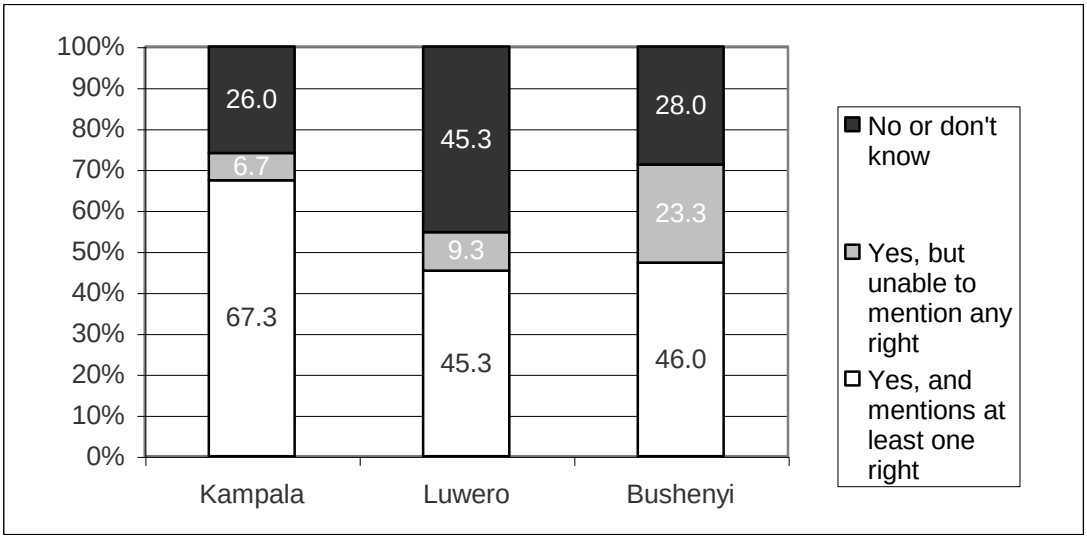
To examine the level of rights awareness amongst patients and health providers, respondents were first asked a general question whether patients have certain rights. If the respondent answered 'yes', he/she was asked to mention which rights he/she thought that patients have. While the administration of the first question is straightforward, the second question required substantial rights awareness amongst the enumerators. Both questions were asked in the end of the interview to benefit from the relatively higher degree of confidentiality between the respondent and the enumerator. The second question was administrated as a semi-structured interview. Respondents would start mentioning aspects of the treatment where they thought that patient's have rights. Enumerators were instructed to interpret these statements and evaluate whether the responses fell into the category of any of the ten patient's rights. To facilitate this question, the enumerators had received special training in the ten patient's rights. Although the outcome of this training was very successful, one has to show some caution when interpreting the results, especially when it comes to the awareness of each of the individual rights. This is because the responses might be biased because enumerators may be better aware of some rights vis-à-vis others.

3.0.2 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 Bushenyi. The headline indicator[3] for rights awareness was therefore chosen as *patients claiming to have rights who are able to identify at least one of the ten rights*. According to this indicator, rights awareness can be said to be significantly higher in Kampala (67%) than in Luwero (45%) and Bushenyi (46%), as illustrated in figure 3.1 on the next page.

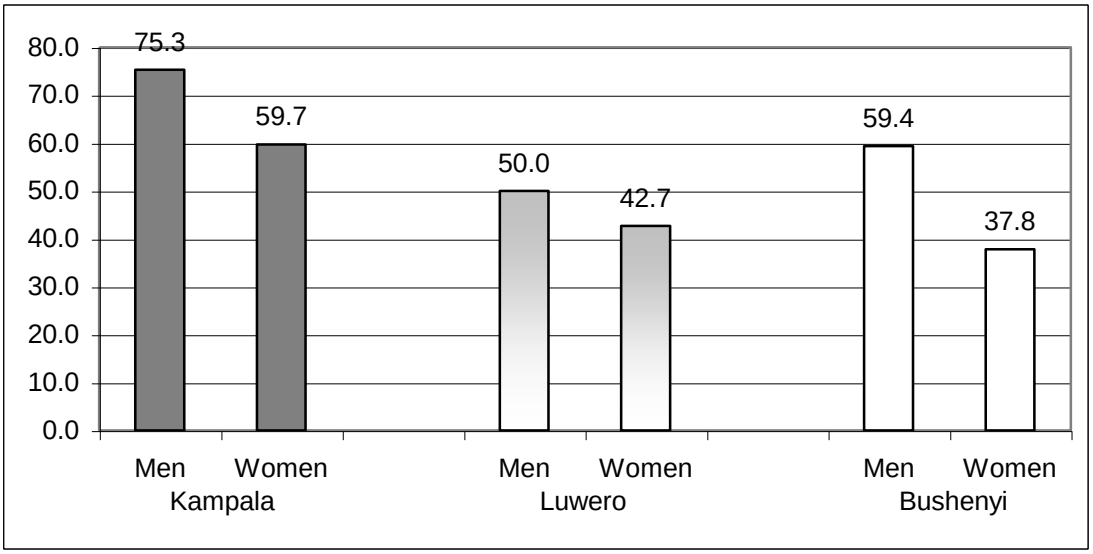
[3] This indicator is considered a reliable measure of rights awareness as it only depended on the mention of at least one right and it is not affected by the awareness of specific rights by the enumerator.

Figure 3.1 Do patients have rights? Patient's response by survey area.



Source: Appendix A.1.

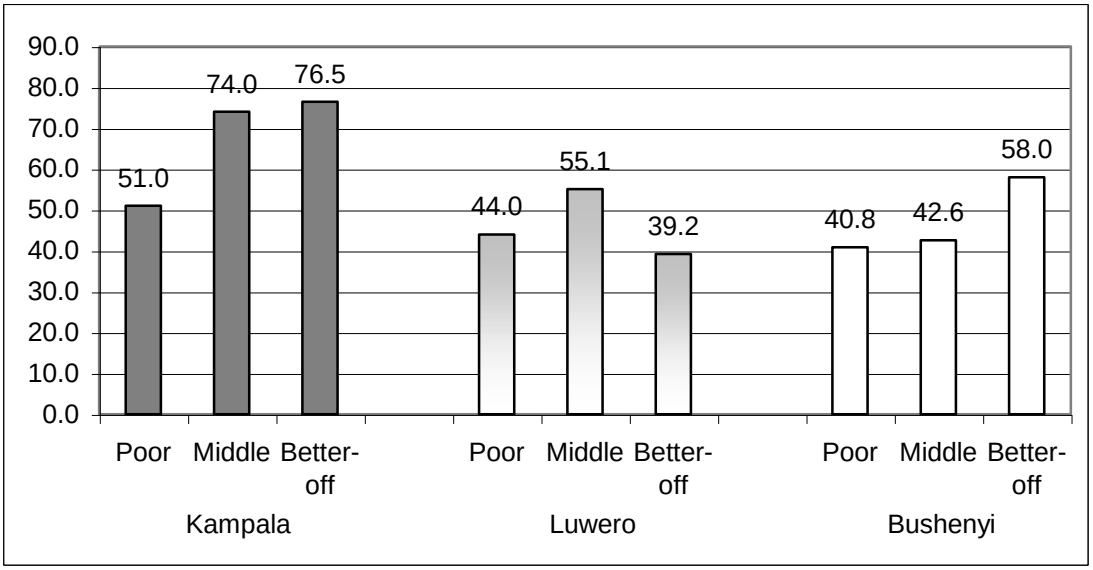
Figure 3.2 Patients claiming rights and mentioning at least one – by sex and area.



Source: Appendix A.2.

Interestingly, men are generally more aware of patient's rights than women, as illustrated in figure 3.2. This was especially the case in Kampala and Bushenyi. Rights awareness was also found to be low amongst the poor socio-economic groups and high amongst the better-off groups, although Luwero is an exception (figure 3.3 refers).

Figure 3.3 Patients claiming rights and mentioning at least one - by poverty and area.



Source: Appendix A.3.

Finally, table 3.1 lists the ten patients rights and sorts them in the order of frequency by which they were mentioned by health providers and patients. Patients were most familiar with the following 4 rights: *Optimum treatment, self-determination, privacy and individual respect.* In contrast, almost none of them mentioned *the right to spiritual and moral comfort, to die in dignity, and redress.* This pattern was broadly similar for health care providers, although the level of awareness was substantially higher. As mentioned earlier, these figures should be interpreted with some caution.

Table 3.1 Awareness of each of the ten patient's rights (%)

	Health providers	Kampala	Luwero	Bushenyi
Optimum treatment	46	45	30	31
Self-determination	50	19	13	7
Privacy	62	15	5	13
Individual respect	55	11	5	8
Equal treatment	45	9	6	4
Participation and representation	34	7	1	0
Right to know	55	5	7	2
Redress	28	3	1	0
Die in dignity	22	1	0	0
Spiritual and moral comfort	28	1	3	0

Source: Appendix A1 and A4.

3.1 The Right to Individual Respect

All patients have the right to have their lives, bodies and personality respected in the course of their treatment (humane treatment). (UNHCO, 2002).

> *Your rights are only for rich people, what can a poor woman like me do?*
> Patient, Luwero Health Centre Kasana – Luwero.

3.1.1 Interpretation of the right to individual respect

The right to individual respect is fundamental for human interaction in general, and for the relationship between patient and health worker, in particular. To increase understanding about this right, consider the following examples:

A health worker does not respect the patient's right to individual respect, if he or she:

a) asks personal questions about the patient's life, which are not directly related to the health of the patient (e.g. about personal relationships or income).
b) makes comments about the size of the patient's body (too big or too small) and makes suggestions as to why the body appears as it does (e.g. HIV/AIDS or too much eating).
c) makes sexual comments or behaves in a way, which implies sexual interest (e.g. touches the patient in a non-professional manner or asking them to undress when this is not necessary).
d) makes comments about the patient's personality (e.g. ideas, opinions and beliefs), which are not related to the patient's health.

Two questioners were designed to capture important aspects of the right to respect. First, patients were asked whether health workers made any comment about their personal appearance. If a positive response was given, a second question addressed the appropriateness of the comments made. Six different options were available:

1. Personal hygiene
2. Way of talking
3. Personal looks
4. Age
5. Sexual
6. Other

When interpreting the answers, options 1 and 5 were considered appropriate and options 2, 3 and 4 inappropriate.

3.1.2 Survey findings

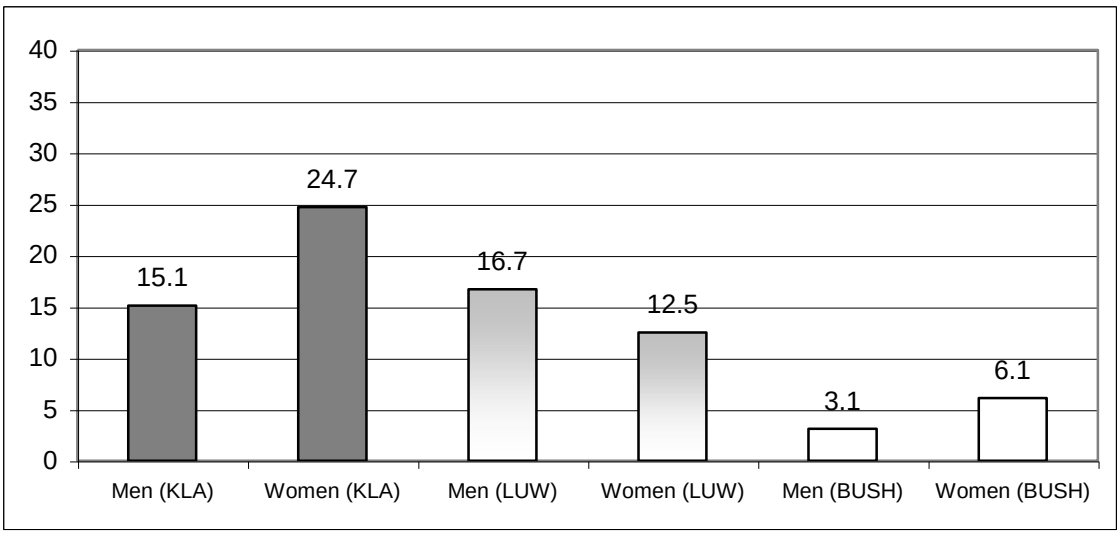
Table 3.2 Summary table for 'The Right to Individual Respect' (% distribution)

	Health Providers	Health Users		
		Kampala	Luwero	Bushenyi
Awareness of rights				
Right to Individual respect	55.6	11.3	5.3	8.2
Behaviour				
Health worker made comments		20	14.0	4.8
Inappropriate comments		12.6	8.6	3.3
Number	18	150	150	146

Source: Appendix A.

Patient's awareness about their right to individual respect is relatively limited ranging from 5% in Luwero to 8% in Bushenyi and 11% in Kampala. In contrast to responses by patients, more than half of the health providers interviewed were aware of this right.

Figure 3.4 Patients who received comments from health worker by sex



Source: Appendix A.2.

As illustrated in figure 3.4, women were more likely to receive comments from health workers than men, especially in Kampala and Bushenyi. There was no noticeable difference by sex in Luwero.

As mentioned earlier, a distinction was made between appropriate and inappropriate comments. Of the 30 patients in Kampala who had received comments from the health worker, 18 mentioned comments about personal looks, which is considered inappropriate, moreover, 13 of these patients were women. This finding suggests that health workers are less likely to show respect towards women than men. Gender discrimination was also found in Luwero, where 9 out of 13 comments about personal looks were given to women, and in Bushenyi where 5 out of 7 in this group were women.

According to the data from the health providers, 42% considered comments about patient's way of talking, looks and age as appropriate. The misunderstanding of health workers about what is appropriate or not partly explains the number of inappropriate comments patients received.

In summary, patient's awareness about the right to individual respect is low. Women are more likely to have the right to individual respect violated when health workers make comments about their personal looks. It was also found that health providers lack a clear understanding about which comments are appropriate and which are not.

3.2 The Right to Receive Equal Treatment

A patient has the right to receive equal treatment irrespective of economic or social status, age, sex, or type of disease. (UNHCO, 2002).

> *We are poor. I am poor, I have no help and I have children. They are orphans and they are in the village with no help at all. Maybe with your interviews you can help us in dealing with poverty and accessing treatment.*
>
> Patient, Kibuli Hospital - Kampala.

3.2.1 Interpretation of the right to receive equal treatment

Discrimination because of sex, age, tribe, clan, race, socio-economic status and religion is, unfortunately, quite common in many societies and situations, including health care treatment. Participatory evidence from Uganda, suggests that women and poor people are being negatively discriminated against when they access health care. One reason for this is an assessment by health workers about the patient's ability to pay user fees and other unofficial fees. Patients who looked less likely to be able to pay such fees, such as women and poor people, where not receiving appropriate treatment and had to wait longer than other patients (MFPED, 2000, 2001c).

This survey assessed the right to equal treatment by asking patients directly whether they felt that they were treated differently. In case patients felt this way, they were asked to state the reason for this discrimination (i.e. whether it was due to sex, age, tribe, clan, race, illness, socio-economic status, religion or other). This question allowed multiple answers. A question was also asked about a concrete situation, namely whether the order of the queue was respected by the health workers.

3.2.2 Survey findings

Table 3.3 Summary table for 'The Right to Equal Treatment' (% distribution)

	Health Providers	Health Users		
		Kampala	Luwero	Bushenyi
Awareness of rights				
Right to Equal Treatment	44.4	8.7	6.0	4.1
Behaviour				
Patients are treated differently	27.8	6.7	5.3	5.5
Order of queue not respected	0.0	14	10.0	8.2
Number	18	150	150	146

Source: Appendix A.

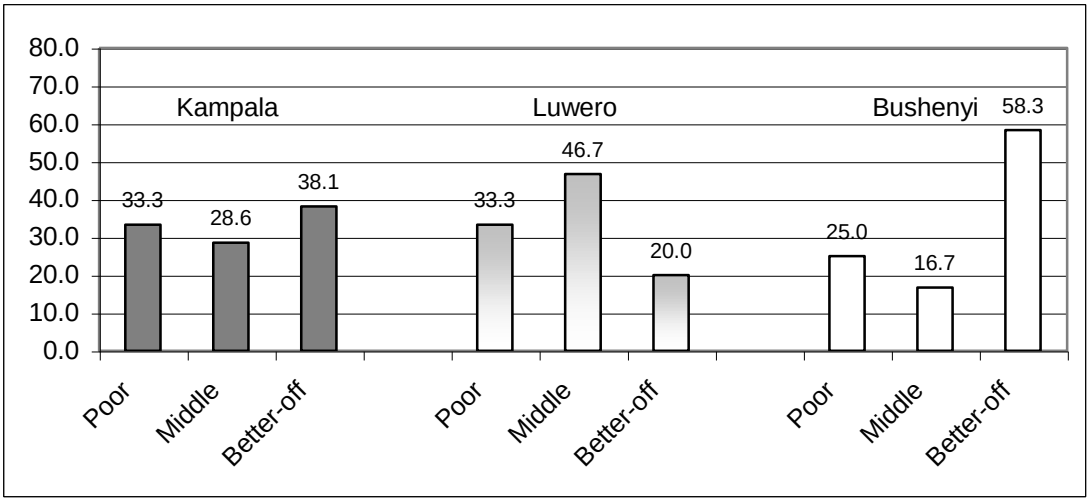
Patients generally lack awareness about the right to equal treatment. 9% of respondents in Kampala mentioned this right, compared to 6% in Luwero and 4% in Bushenyi. In comparison, 44% of the health providers interviewed expressed awareness about this right. A gender distribution of the responses from patients shows that in Kampala and Bushenyi women were less aware about this right than men. In those two areas the group of better-off respondents are also more aware of this right than the middle income and poor groups (39% in Kampala and 50% in Bushenyi).

About 95% of the patients said that they had received equal treatment. In the case of the remaining 5%, it was found that this was primarily due to illness, which can possibly be justified because some illnesses requires more urgency than others.

Despite the fact that most patients said not to have experienced differential treatment, 3 of the 18 health providers interviewed, acknowledged that they do treat patients differently, either because of age or because of socio-economic status.

A majority of the respondents said that the order of the queue was respected. However, 14% of the Kampala respondents said that this was not the case compared to 10% in Luwero and 8% in Bushenyi. The queue was almost always respected in private health units. Unsurprisingly, all health providers interviewed claimed that the order of the queue is always respected.

Figure 3.5 Order of queue was not respected – by socio-economic group



Note: The total number of observations was: Kampala (21), Luwero (15) and Bushenyi (12).
Source: Appendix A.3.

In contrast to the participatory findings cited earlier, there was no systematic gender discrimination in terms of respect of the queue. In Kampala there was no difference by sex. In Luwero women were more likely to face discrimination, while in Bushenyi it worked the other way around. Similarly, the data could not support the hypothesis that the poorest groups are discriminated against (see figure 3.5). There were also no differences by type of health unit.

In summary, patients have limited awareness about the right to equal treatment, while health providers have more knowledge. Amongst the patients, the men and the better-off seems showed most awareness. Few patients felt they were treated differently while almost one third of the providers actually said that they do treat patients differently. A number of patients felt that the queue was not respected, but it was not possible to conclude from the data that the poor people or women are particularly affected.

3.3 The Right to Optimum Treatment

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 previous doctor refused to give me the information about my health when changing to another clinic. If I had known I had rights I was going to take the doctor to the court of law.*
>
> Brain tumour patient at Abii Clinic, Kampala.

3.3.1 Interpretation of the right to optimum treatment

The right to optimum treatment is challenged in the Ugandan context where there are 20,228 people per doctor (UN Uganda, 2000). This reduces patient's possibilities in choosing their own medical practitioner to a minimum. Moreover, the selection of the type of health unit a patient can access is determined by physical proximity to the clinic and the patient's ability to pay.

The right to optimum treatment presented a great challenge to the survey because there was little opportunity to follow medical interventions over time. Therefore, due to the complexity of the issues covered by this right, the questionnaire only covered partial aspects of it. Patients were asked whether a stool or blood test had been taken, controlling for the relevance of this test given the reported illness of the patient. Blood test was seen as a requirement if the patient reported malaria/fever and stool test if the reported illness was diarrhoea or intestinal infection. Patients were also asked about the reasons why the test had not been taken, such as lack of equipment, lack of time/personnel or because the patient could not afford it.

3.3.2 Survey findings

Table 3.4 Summary table for 'The Right to Optimum Treatment' (% distribution)

	Health Providers	Health Users		
		Kampala	Luwero	Bushenyi
Awareness of rights				
Right to Optimum Treatment	61.1	45.3	30.0	30.8
Behaviour				
No malaria test when relevant	11.1	13.3	18.8	44.3
No stool test when relevant	16.7	0.0	25.0	14.3
Number	18	150	150	146

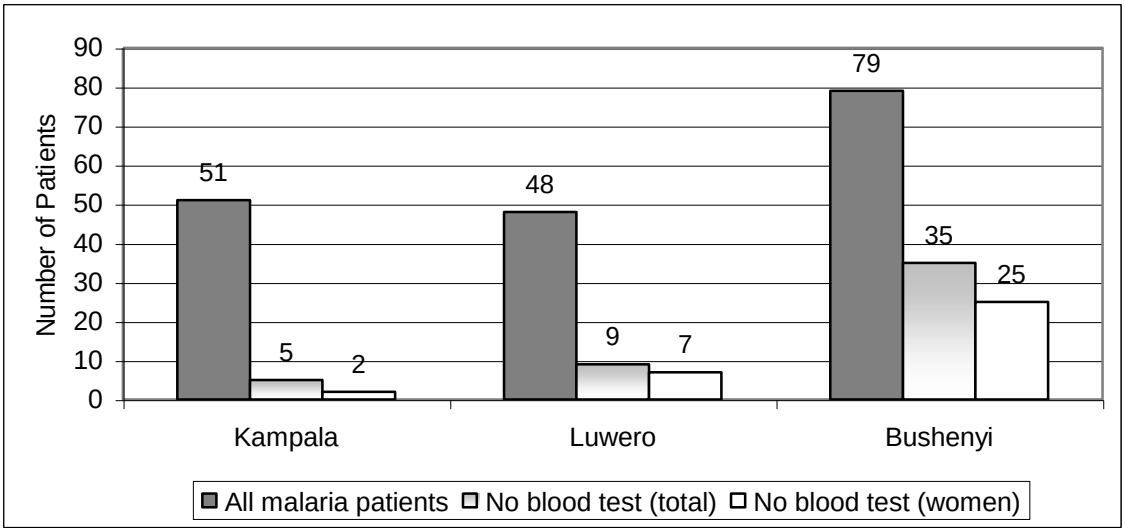
Appendix A.

Of the ten rights, the right to optimum treatment was the one patients were most familiar with. More than one third of the respondents identified the right to optimum treatment. The biggest share was found in Kampala (45%), while respondents in Luwero and Bushenyi had a relatively lower level of awareness (30-31%). A majority of providers (61%) were also aware of the right to optimum treatment.

Was a test taken when relevant?[4]

Strikingly, up to 44% of the 79 malaria patients in Bushenyi did not get a blood test. When asked why a test was not taken, 91% of these patients cited lack of time/personal. Furthermore, 19% of the 48 malaria patients in Luwero did not receive a blood test. When asked why, 3 out of 4 of the patients answered 'don't know'. In Kampala, only 5 out of 40 malaria patients did not receive a blood test. As figure 3.6 illustrates, female malaria patients were significantly more likely not to receive a malaria test. 71% of the malaria patients not tested in Bushenyi were women and 78% in Luwero. There was no sex difference in Kampala.

Figure 3.6 Number of malaria patients not receiving a blood test by sex.



Source: Appendix A.2.

[4] This section focuses on malaria test, since only 4 patients did not receive a stool test when relevant.

In terms of socio-economic status, the 35 Bushenyi patients not receiving a malaria test come from all three income groups. There is some over-representation amongst the better-off group in the case of the 9 patients in Luwero, but the sample size is rather small. There was no socio-economic difference in Kampala.

There are also interesting observations to make when the type of health unit is taken into account. In Bushenyi, 89% of the patients not receiving malaria test were treated in a Government health unit. In Luwero, more than half were treated in NGO units. In Kampala 4 out of the 5 relevant cases were from a Government health unit.

From the health provider data we see that 2 of the 18 health units visited admitted not having the necessary resources to perform a blood test. Both of these health units are Government health units. This explains why a test was not taken if the patient went to a Government clinic, but the patients in Bushenyi were typically not aware of why they were not tested.

In summary, awareness about the right to optimum treatment is relatively good for both patients and providers. This survey measured the right to optimum treatment by measuring the extent to which malaria patients receive a blood test. It was found that almost half of the malaria patients in Bushenyi did not receive this test. A majority of the patients were from Government health units and they were women. Evidence from both patients and providers suggest that the Government health unit in Bushenyi does not have the necessary resources to perform a malaria test.

3.4 The Right to Know

The right to know means that patients have the right to;

a) know all possible information necessary to understand the condition;

b) receive from their practitioner a fully comprehensive record of the course of their condition, both the nature and results of tests, diagnosis, examinations and treatment already provided and the aims, methods, content, risks and prognosis of tests and treatments to be carried out as well as possible alternatives (choices).

c) know whether the medical intervention received has an element of research, experimentation or similar aim.

d) ask the medical institution for access to records regarding their medical treatment and to be provided with copies of medical treatment.

e) know the name, qualifications and role of the main doctor and other medical practitioners who participate in your treatment.

f) *receive a detailed report of the costs of your treatment from the medical institution and information about the public subsidy of the medical costs.* (UNHCO, 2002):

> *I don't know if I was treated by a doctor or a nurse or what. I can't tell the difference because they are not wearing uniform…*
>
> Patient, Luwero Health Centre Kasana - Luwero.

3.4.1 Interpretation of the right to know

The right to know refers to the right patients have to access information about the type of illness they have and its possible causes. For example, a person who has an allergic reaction to lactose products needs to be told about it in order not to experience the

same problem again. This right also covers information related to the treatment a patient is receiving as well as the course of their condition. For example, one of the patients interviewed was a pregnant woman whose water bag broke in the eight month of pregnancy. She had received an induction and was about to deliver, however, she did not know whether the baby was alive or not, or what kind of drugs the nurses were giving her. She had asked for information, but the nurses refused to give it to her because 'she was not a doctor and, hence, she would not understand'.

Other aspects of this right cover those related to patients used as test patients, but without their knowledge and consent. This is commonly found in the case of HIV/AIDS patients who sometimes are unaware that medical research is being carried out on them.

Four aspects of the right to know were captured in the survey: First, whether the health worker told the patient about the kind of illness that he/she suffered from. Secondly, whether the cause of illness was explained. Thirdly, whether the patient was told about potential side effects. And finally, whether the patient was told about the cost of treatment before receiving it.

3.4.2 Survey findings

Table 3.5 Summary table for 'The Right to Know' (% distribution)

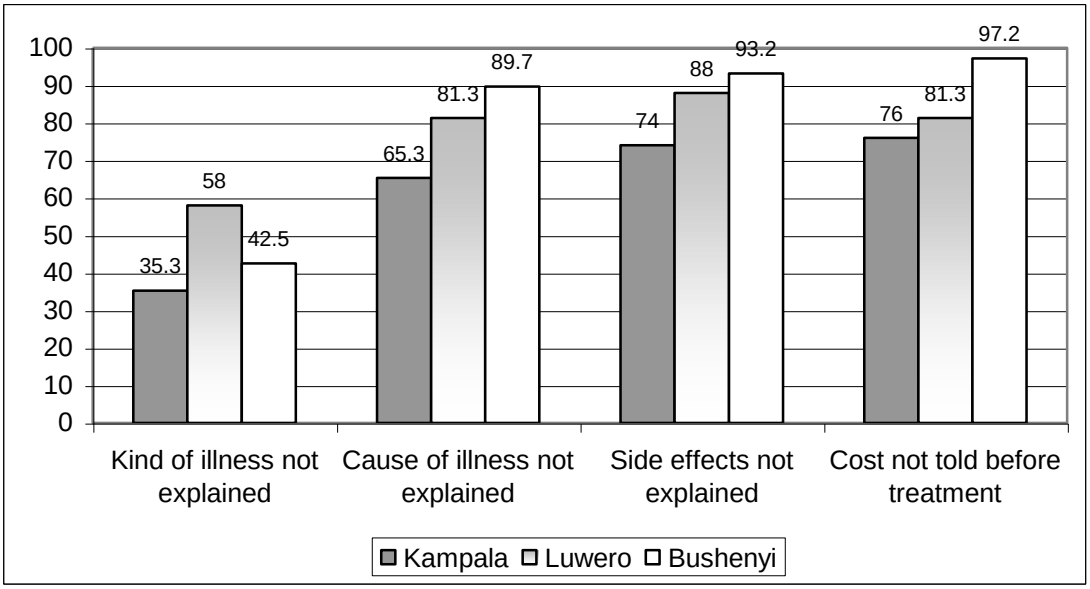
	Health Providers	Health Users		
		Kampala	Luwero	Bushenyi
Awareness of rights				
The Right to Know	55.6	5.3	7.3	2.1
Behaviour				
Kind of illness not explained	-	35.3	58.0	42.5
Cause of illness not explained	5.6	65.3	81.3	89.7
Side effects not explained	11.9	74.0	88.0	93.2
Cost not told before treatment	27.8	76.0	81.3	97.2
Number	18	150	150	146

Source: Appendix A.

The right to know was only mentioned by 2-7% of the patients. In contrast, more than half (56%) of the health providers acknowledged the right to know.

The most basic information a patient should receive from a health practitioner is the type of illness he/she has. Nevertheless, almost half of the patients were never told. The highest incidence of uninformed patients was found in Luwero (58%). In Bushenyi less than half of the respondents did get this information, while in Kampala it was around one third. Interestingly, women were more likely to have their condition explained than men in Kampala and Bushenyi, while the opposite was the case in Luwero. There was no systematic difference in the answers by socio-economic status or type of health unit.

Figure 3.7 Various aspects of treatment according to patients (% distribution)



Source: Table 3.4.

Most patients were never told about the cause of their illness: 9 out of 10 patients in Bushenyi, 4 out of 5 patients in Luwero, and 2 out of 3 patients in Kampala. Socio-economic status matters in this case. The better-off are more likely to get this information than the other two socio-economic groups. Similarly, patients from private health units were more likely to receive explanation. There was no systematic difference by sex.

Strikingly, almost none of the patients were informed about the possible side effects of the medication prescribed. Patients in Luwero and Bushenyi were less likely to be told about side effects than those in Kampala. The same was the case for patients in government and NGO health units. There was no systematic difference by sex or socio-economic group. This finding is a strong contrast to the answers given by health care providers: Around 90% of the providers said that information about side effects of medication is given to the patients.

None of the patients in Bushenyi were told about the cost before treatment, while around 4 out of 5 patients did not get this information in Kampala and Luwero. This contrasts with the statements by health care providers, where 72% claimed to give this information to their patients.

In summary, patients are generally unaware of the right to know, and as a consequence this right is frequently violated. A majority of patients are never told about the kind of illness they suffer from, the cause of this illness, the side effects of medication prescribed nor the cost before treatment. In contrast, more than half of the health providers are aware of the right, and although they claim to respect it, the evidence from patients revealed that this is not the case.

3.5 The Right to Self-determination

As a patient, based on your own free will, you have the right to select or reject tests, treatment or other medical intervention with the co-operation and advice given in good faith by medical practitioners. (UNHCO, 2002).

3.5.1 Interpretation of the right to self-determination

The right to self-determination enables patients to take active part in their own treatment. It also gives the patient the opportunity to choose what he/she may consider to be best for him- or her. An example is the right patients have to decide whether they want to take an HIV/AIDS test or not. This right also protects health workers who inform their patients about ongoing tests, ensuring that they understand the nature of these tests, to avoid potential complains from patients. The right to self-determination was assessed by asking two questions. First, whether patients had been offered alternative medication. Secondly, whether they felt that had a say in choosing their medication.

3.5.2 Survey findings

Table 3.6 Summary table for 'The Right to Self-determination' (% distribution)

	Health Providers	Health Users		
		Kampala	Luwero	Bushenyi
Awareness of rights				
The Right to Self Determination	50.0	18.7	13.3	6.8
Behaviour				
Alternative medication offered	94.4	10.7	6.7	4.1
Patient have a say in choosing medication	55.6*	20.7	37.3	31.5
Number	18	150	150	146

Note: *) Providers were asked whether patients can choose their own medication.
Source: Appendix A.

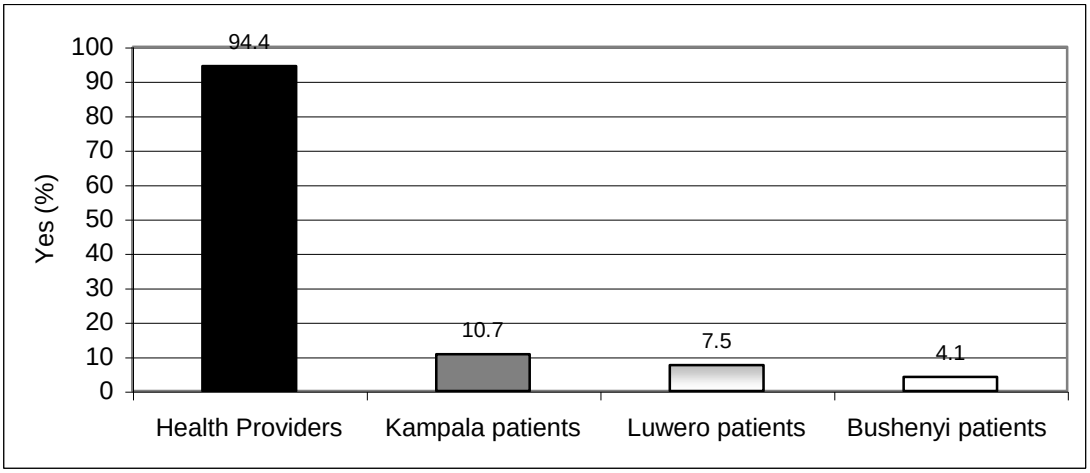
Less than 20% of the patients identified the right to self-determination. Of these, 19% were interviewed in Kampala, 13% in Luwero and 7% in Bushenyi. Half of the providers interviewed were aware of the right to self-determination.

According to the survey results patients are not offered alternative medication generally. Only 11% in Kampala, 7% in Luwero and 4% in Bushenyi said that this was the case. Amongst those who were offered there was an over-representation by the best-off socio-economic group.

Again, data collected from providers differ dramatically from the respondents: Almost all of the providers said that they offer alternative medication to their patients, as illustrated in figure 3.8.

Less than a third of the patients felt that they had a say in choosing their own medication. This was less common in Kampala than in Bushenyi or Luwero. In contrast, more than half of the providers claim that patients can choose the medication they want to take.

Figure 3.8 Health providers vs. patients: Was alternative medication offered?



Source: Table 3.5.

In summary, health providers are more aware of the right to self-determination than patients. Patients are unlikely to be offered alternative medication and few feel that they have a say in choosing it. Health providers claim that alternative medication is offered.

3.6 The Right to Privacy

As a patient you have the right to privacy. You have the right that information about you should not be disclosed without your permission except those directly engaged in your medical treatment without your permission. (UNHCO, 2002).

3.6.1 Interpretation of the right to privacy

The right to privacy can be interpreted in two ways. The first relates to information management, and the second to patients access to proper infrastructure during examination. This survey focused on the second aspect by asking patients whether they felt comfortable with all the persons present in the room while being examined or not.

3.6.2 Survey findings

Table 3.7 Summary table for 'The Right to Privacy' (% distribution)

	Health Providers	Health Users		
		Kampala	Luwero	Bushenyi
Awareness of rights				
Right to Privacy	61.1	14.7	4.7	13.0
Behaviour				
Lack of privacy during examination	16.7	6.7	0.7	3.4
Number	18	150	150	146

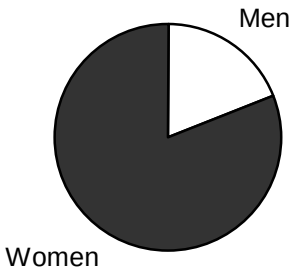
Source: Appendix A.

Luwero had the lowest level of awareness about this right. Men were generally more aware than women in Kampala (68%) and in Bushenyi (58%). Socio economic analysis shows that the better-off are most aware of the right (Kampala 46% and

Bushenyi 42%). Providers' awareness about the right to privacy is high. More than half of the providers interviewed were aware of the right to privacy.

Most patients felt their privacy was respected during examination. There was a considerable gender bias amongst those expressing concern about privacy. 13 out of the 16 patients lacking privacy were women (see figure 3.9). In addition, most of the patients who lacked privacy were examined in Government units (10 of the 16).

Figure 3.9 Sex distribution of patients lacking privacy during examination



Source: Appendix A.2.

Results from the provider's questionnaire tally with the information gathered from patients: 83% of the providers explained that patients are examined in privacy. The remaining 17% who said to have more than one patient examined at the same time all worked in government health units.

In summary, male and better-off patients are most aware about this right; nevertheless, when the right is violated it is the women who are mostly affected. Health providers are more aware about the right to privacy than patients.

3.7 The Right to Participation and Representation

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 or groups. (UNHCO, 2002).

3.7.1 Interpretation of the right to participation and representation

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, UNHCO represents an example of patient's representation at the national level. In this survey, patients were asked if they participate in any health related affairs, meetings, organizations or groups.

3.7.2 Survey findings

Table 3.8 Summary table for 'The Right to Participation and Representation' (%)

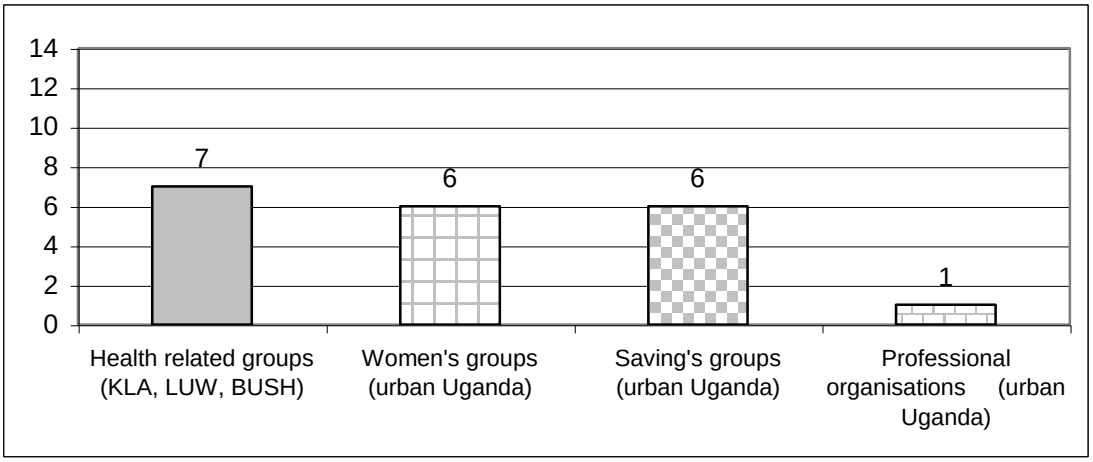
	Health Providers	Health Users		
		Kampala	Luwero	Bushenyi
Awareness of rights				
Right to Participation and Representation	33.3	6.7	0.7	0.0
Behaviour				
Participate in health groups	-	6	6.7	8.9
Are aware of health groups	50.0	-	-	-
Number	18	150	150	146

Source: Appendix A.

General results shows that almost none of the health users recognised the right to participation and representation. One out of every three provider expressed knowledge of the right.

Participation rates for health groups are relatively high at 6-9% depending on the location. Participation in health related affairs do not depend on the level of awareness about the right. For example, Bushenyi has the highest level of participation, but the lowest level of awareness. The better-off have higher participation rates in Kampala and Luwero. Participation rates are also typically higher for patients seeking private health care. In comparison, 6% of urban Ugandans participate in women's groups, 6% in Savings groups and 1% in professional organisations (e.g. farmers groups) (UNHS 1999/00) – see also figure 3.10. Around half of all providers are aware of health related groups.

Figure 3.10 Participation rates for different types of organisations (percent)



Note: Data on health related groups is from 2002 UNHCO Baseline survey, while the data on women's groups, saving's groups and professional organisations are from Uganda National Household Survey 1999/2000 (urban areas only).
Source: Appendix A.1 and author's own calculations based on UNHS (1999/00) data.

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.

3.8 The Right to Redress

Every patient has a right to receive redress and have their grievances addressed by health institutions. (UNHCO, 2002).

> *The doctor made the mistake when he gave my child the injection, because he was drunk. Now the leg has swollen and busted. They told me to go to a private hospital, but I have no money, so I will just go home with the kid and hope he does not die.*
>
> Patient, Luwero Health Centre Kasana - Luwero.

3.8.1 Interpretation of the right to redress

The right to redress involves, amongst others, the right patients have: to demand gratification if they were injured during treatment; to have access and mechanisms for complain and; to receive an official apology from the health unit. The quote given at the beginning of this section is an obvious example of violation of this right.

To analyse the respect of this right, patients were asked whether they were aware of any place to complain in case the service delivered was poor or not satisfactory.

3.8.2 Survey findings

Table 3.9 Summary table for 'The Right to Redress (%)

	Health Providers	Health Users		
		Kampala	Luwero	Bushenyi
Awareness of rights				
Right to Redress	27.8	2.7	1.3	0.0
Behaviour				
No place to complain	16.7	56	46.7	86.3
Number	18	150	150	146

There is almost no patients' awareness about the right to redress. Only a quarter of the providers knew about this right.

More than half of the respondents did not know of any place to complain, with up to 86% of the respondents not knowing in Bushenyi. Women and the poor were significantly less likely to know where to complain in all three locations, while men were more likely to suggest that complaints should be addressed to the management of the health unit.

On the other hand, 84% of the interviewed providers said that patients complain about the services. Complaints were said to be given directly to the management of the health unit (67%) or the senior health officer (39%).

3.9 The Right to Die in Dignity

Every patient has the right to die in dignity. (UNHCO, 2002).

3.9.1 Interpretation of the right

The aspects included in the right to die in dignity involve ethical and legal principles. The legal principles include a patient's right to access treatment until the last minute of his/her existence. This includes writing a will if relevant, and expressing wishes about organ donation. The ethical aspects are more related to the individual's perceptions, opinions and beliefs. These include the right to decide over funeral rituals (e.g. cremation of the body).

This survey covers the ethical aspects. The following question was asked and multiple options were allowed: When should the treatment of a patient be terminated? Should treatment stop if: 1) the patient is terminally ill; 2) he/she cannot understand or think anymore; 3) the patient is dead; 4) he/she has no control over his/her body; 5) he/she cannot afford to pay and; 6) the family asks for it. The purpose of asking this question was to capture the perceptions of patients and health providers in terms of which factors could justifiably stop a patient from receiving treatment.

Due to the complexity of the question, the variable "when the patient is dead", was used as a control variable to measure whether the respondents understood the question or not, and whether they were still actively involved in the interview rather than giving mechanical answers. Over 98% of the respondents mentioned this option showing that patients had understood the question and were alert.

3.9.1 Survey findings

Table 3.10 Summary table for 'The Right to Die in Dignity' (%)

	Health Providers	Health Users		
		Kampala	Luwero	Bushenyi
Awareness of rights				
Right to Die in Dignity	22.2	0.0	0.0	0.0
Perceptions				
Treatment should stop when:				
The patient cannot afford it	11.1	18.7	6.7	6.2
The family asks for it	22.2	9.3	9.3	16.4
The patient is dead	94.4	95.3	98.7	98.9
Number	18	150	150	146

Source: Appendix A.

When asked directly, none of the respondents mentioned the right to die in dignity. On the other hand 22% of the providers did mention this right.

Regarding people's perceptions about when treatment should stop, the most frequently mentioned options were 'when the family asks for it' and 'when the patient cannot afford it'. Thus, patient's motives are a combination of ethical and pragmatic considerations, as explained below:

People in Kampala were more likely to mention lack of resources (18%), compared to Luwero (7%) and Bushenyi (6%). In Bushenyi, this view was only predominant amongst those who could afford it: the better off (67%) and the middle income (33%). Similarly, in Kampala, this view was expressed primarily (75%) by patients attending private health units. In contrast, the view that the family should decide was relatively more predominant in Bushenyi (16%) compared to Kampala and Luwero (both 9%). Most patients in Kampala and Bushenyi who mentioned the family as an option belong to the middle-income group. In the case of the providers, 22% agreed treatment should stop if the family asks for it, and 11% said when the patient could not afford to pay any more.

In summary, there is no patient awareness about the right to die in dignity. Similarly, less than one quarter of the providers mentioned this right. On the question of when treatment should stop, patients in Kampala and to some extent the better-off generally agreed that treatment should stop when patients lack resources, while the middle income group considered it a family decision.

3.10 The Right to Spiritual and Moral Comfort

Patients have the right to receive or decline spiritual and moral comfort including the help of a minister of an appropriate religion (UNHCO, 2002).

> *The first thing the nurse did when I was registering was to ask me my religion, even before my name. Why are patients asked about their religion before they are admitted to the hospital?*
>
> Patient, Nsambya Hospital - Kampala.

3.10.1 Interpretation of the right to spiritual and moral comfort

The right to moral and spiritual comfort means that patients should not be imposed to seek spiritual or moral comfort based on the religious identity of the health unit or the health worker. Moreover, religion should not stop any patient from accessing health services. Lack of facilities or inconvenient behaviour should not be used as an excuse to prevent patients from performing their religious practices. For example, Catholic supported NGO health units should not stop Muslims from praying three times a day.

The survey approached this right by asking patients and health providers about their perceptions as to who should decide on the spiritual and moral comfort a patient can access when admitted to a health unit. The following options were given: Health unit, family, church, individual, political leader, Local Council and other.

3.10.2 Survey findings

Table 3.11 Summary table for 'The Right to Spiritual and Moral Comfort' (%)

	Health Providers	Health Users		
		Kampala	Luwero	Bushenyi
Awareness of rights				
Right to Spiritual and Moral Comfort	27.8	0.7	2.7	0.0

Perception				
Who should decide on spiritual / moral comfort?				
Individual	88.9	75.3	66.7	77.4
Family	16.7	27.3	42.0	17.8
Health unit	11.1	16	18.7	16.4
Church/mosque	0.0	12	6.7	4.1
Number	18	150	150	146

Source: Appendix A.

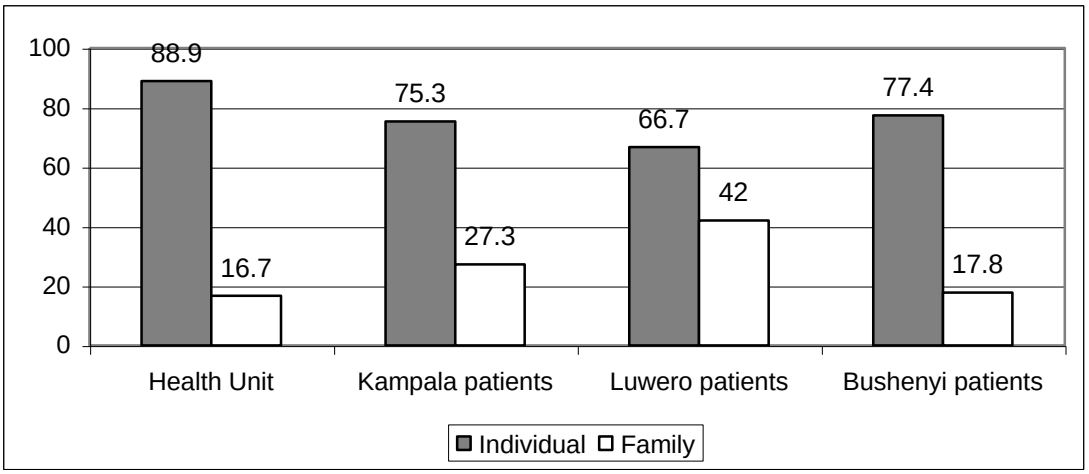
There is no awareness about the right to receive moral or spiritual comfort amongst patients. Health providers are more aware, but not overwhelmingly: Only 28% identified access to moral and spiritual comfort as a patient's right.

Majority of respondents believe that it is the *individual* who should decide over the type of moral or spiritual comfort a patient can access. Disaggregated data shows that this is more predominant in Kampala and Bushenyi than in Luwero. *Family* was the second most frequent option, with 42% of patients mentioning this in Luwero, 27% in Kampala and 18% in Bushenyi. Fewer patients believe *health units* should decide over the matter, 18% in Luwero, 16% in Bushenyi and 16% in Kampala. Some patients also mentioned the church/mosque, especially in Kampala, but nobody mentioned Political Leader or Local Council.

Comparison by sex shows that men were more likely to say individual, while women said family. There were no observable differences in these answers by socio-economic groups.

Providers agreed that the decision over moral and spiritual comfort should be taken primarily by the individual (89%). Family and health unit also have a small role, but nobody mentioned church/mosque.

Figure 3.11 Who should decide over religious or moral comfort of a patient? (%)



Source: Appendix A.

In summary, the right to choose over the type of moral or spiritual comfort is seen by the patients mostly as an individual decision. This opinion is shared by the providers.

Chapter 4. Quality Aspects of Health Care

In addition to information about patient's rights, the 2002 UNHCO Baseline Survey also measured some related aspects of the quality of health care patients had received. These aspects include: waiting time (section 4.1), consultation time (section 4.2), trust in health worker (section 4.3) and evaluation of treatment received (section 4.4).

4.1 Waiting Time

Table 4.1 Waiting Time according to health providers and patients (percentage).

	Health Providers		Patients		
Waiting time	Quiet period	Busy period	Kampala	Luwero	Bushenyi
0 - 10 min.	83.3	11.1	46.0	65.3	41.1
10 - 30 min.	5.6	55.6	27.3	14.0	27.4
30 - 60 min.	5.6	16.7	4.0	6.0	20.5
One to two hours	5.6	5.6	15.3	6.0	10.3
Two to six hours	0.0	11.1	7.3	6.7	0.7
More than six hours	0.0	0.0	0.0	2.0	0.0
Number	18	18	150	150	146

Source: Appendix A.1.

A majority of the interviewed patients waited for less than 10 minutes before receiving treatment. Less than a third of them waited for more than half an hour. Patients in Bushenyi wait slightly longer than in Kampala and Luwero. The information given by health providers confirmed the patients' statements. Government patients wait longer than those attending NGO or private health units. Poor patients in Kampala also tend to wait relatively longer.

4.2 Consultation Time

Table 4.2 Consultation Time (percentage).

	Health Providers	Patients		
Consultation time		Kampala	Luwero	Bushenyi
0 – 5 min.	16.7	20.0	27.3	38.4
5 – 10 min.	33.3	23.3	33.3	26.0
10 – 20 min.	27.8	30.0	22.0	24.7
20 – 40 min.	16.7	19.3	4.0	6.2
40 – 60 min.	5.6	6.0	4.0	4.1
One hour or above	0.0	1.3	9.3	0.7
Number	18	150	150	146

Source: Appendix A.1.

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.

4.3 Trust in Health Worker

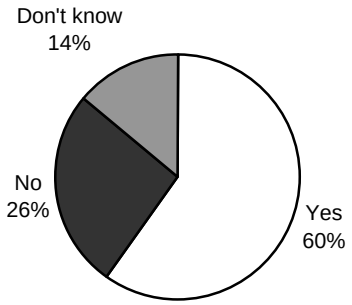
Table 4.3. Did you trust the health worker who gave you treatment? (%)

	Kampala	Luwero	Bushenyi
Yes	95.3	82.7	95.9
No	2.7	9.3	3.4
Don't know	2.0	8.0	0.7
Number	150	150	146

Source: Appendix A.1.

Trust in health worker was almost universal amongst patients in Kampala and Bushenyi, while 17% in Luwero expressed signs of lack of trust. Almost all of the Luwero patients lacking trust in the health worker were treated in Kasana Health Centre, which is a Government Hospital (see figure 4.1).

Figure 4.1 Trust in Health Worker- Kasana Health Centre (GoU), Luwero T.C.



Source: Appendix A.4.

One enumerator at Kasana explained that during interviews the health staff felt threatened by his presence and denied being interviewed. Moreover, the health personnel did not work on the second day of the interviews because they feared that the survey was commissioned by the Ministry of Health to examine the quality of services. The enumerator also discovered that one of doctors was under heavy alcohol influence and interviews with patients confirmed that this affected the treatment negatively. (See for instance the quote in section 3.8).

4.4 Evaluation of Treatment

Table 4.4. Patient's evaluation of treatment (%)

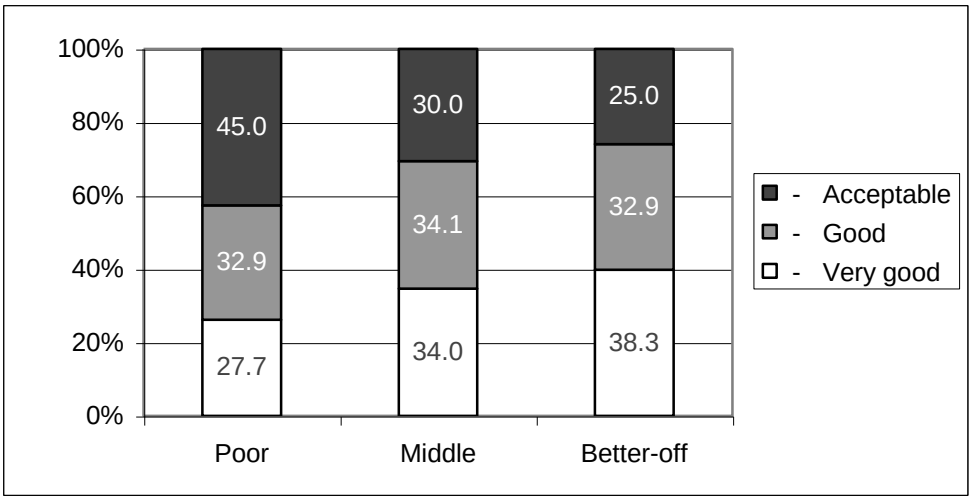
	Kampala	Luwero	Bushenyi
Very good	31.3	16.7	13.7
Good	54.7	61.3	79.5
Acceptable	13.3	14.7	6.8
Bad	0.7	6.7	0.0
Very bad	0.0	0.7	0.0
Number	150	150	146

Source: Appendix A.1.

A majority of patients feel that they receive *good* treatment. Some even said to have received *very good* treatment. Between 7 and 15 percent evaluate the treatment as *acceptable*. Almost none of the patients described their treatment as *bad* or *very bad*. Judged by face value, these statements suggest that the quality of health care in Uganda is very high. However, patients' evaluations depend on their expectations and knowledge about rights. 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' rights are frequently violated during treatment, and if patients knew about these rights, then satisfaction rates would be much lower.

As illustrated in figure 4.2 there were substantial differences in patients' evaluation of their treatment by socio-economic status. The better-off in Kampala and Luwero were significantly more satisfied with the quality of treatment than the poor. In Bushenyi, a majority of the better-off said that services were only acceptable.

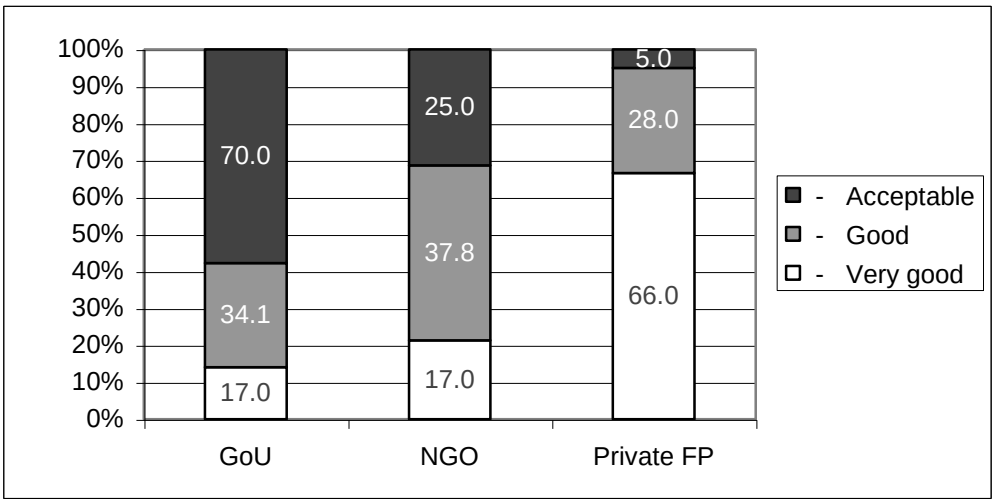
Figure 4.2 Evaluation of treatment by socio-economic status in Kampala (%)



Source: Appendix A.3.

A break-down by type of health unit reveals that satisfaction rates in private health units are much superior to those in Government and NGO units (see figure 4.3). This was the case in Kampala and Luwero, although not in Bushenyi. There were no differences in evaluations by sex.

Figure 4.3 Evaluation of treatment by health unit in Kampala (%)



Source: Appendix A.4.

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APPENDIX A:

SUMMARY STATISTICS

Health Users:
A.1 Sample characteristics
A.2 Answers by sex
A.3 Answers by Socio-economic status
A.4 Answers by type of health unit

Health Providers:
A.5 Summary of health provider's answers

Appendix A.5. Health Unit Codes

Health unit	Type	Size	Health Sub-county
Kampala			
A. International Hospital	Private FP	Big	Kampala Central
B. Kibuli Hospital (1)	NGO	Big (HC IV)	Makindye East
C. Kibuli Hospital (2)	NGO	Big (HC IV)	Makindye East
D. Mulago Hospital (1)	Government	Big (NRH)	Kawempe South
E. Mulago Hospital (2)	Government	Big (NRH)	Kawempe South
F. Adventist M. C.	NGO	Small	Kampala Central
G. Wankulukuku	Government	Small	Rubaga South
Luwero			
H. Patient's Clinic	Private FP	Small	Katikamu North
I. Kasaala Health Centre	NGO	Small (HC III)	Katikamu North
J. Kasana Health Centre	Government	Big (HC IV)	Katikamu North
K. Bishop Ceasar	NGO	Small	Katikamu North
L. Hope Medical Centre	Private FP	Small	Katikamu North
M. Kiwoko Hospital	NGO	Big	Nakaseke
Bushenyi			
N. Bushenyi Health Centre	Government	Big (HC IV)	Igara East
O. Ishaka Adventist Hospital	NGO	Big (HC IV)	Igara East
P. Kyeizooba Farmer's H.C.	Private FP	Small (HC III)	Igara East
Q. Bushenyi Medical Centre (1)	Private FP	Big	Igara East
R. Bushenyi Medical Centre (2)	Private FP	Big	Igara East

APPENDIX B:

SAMPLING ERRORS

Appendix B. Sampling Errors

Two types of errors affect the estimates from a sample survey. Namely; non-sampling errors and sampling errors. Non-sampling errors are the results of mistakes made in implementing the data collection and data processing, such as failure to interview the intended respondent, misunderstanding of the questions on the part of either the interviewer or the respondent, and data entry errors. Although efforts were made during the implementation of the 2002 UNHCO Baseline Survey to minimise this type of error, nonsampling errors are impossible to avoid and difficult to evaluate statistically.

Sampling errors, on the other hand, can be evaluated statistically. The sample of respondents selected in the 2002 UNHCO Baseline Survey is only one of many samples that could have been selected from the same population, using the same sample design and expected size. Each of these samples would yield results that differ somewhat from the results of the actual sample selected. Sampling errors are a measure of the variability between all possible samples given the sample design. Although the degree of variability is not known exactly, it can be estimated from the survey results.

A sampling error is usually measured in terms of the standard error for a particular statistic (mean, percentage, etc.), which is the square root of the variance. The standard error can be used to calculate confidence intervals within which the true value for the population can reasonably be assumed to fall. For example, for any given statistic calculated from a sample survey, the value of that statistic will fall within the range of plus or minus two times the standard error of that statistic in 95 percent of all possible samples of identical design and size.

Since the respondents were interviewed as they left the health unit, the sample selected can be classified as a simple random sample. The variance for any estimate, $\hat{\theta}$, is therefore given by the following formula:

$$\text{var}(\hat{\theta}) = \frac{\hat{\theta}(1-\hat{\theta})}{n-1}(1-\frac{n}{N}) \qquad \text{(B.1)}$$

Where *n* is sample size and *N* is the population size.

Assuming that $\hat{\theta}$ approximately follows a normal distribution, the approximate confidence interval can be estimated as:

$$\hat{\theta} \pm u_{1-\alpha/2}\sqrt{\text{var}(\hat{\theta})} \qquad \text{(B.2)}$$

Where 1-α is the coefficient of confidence.

To illustrate the use of these formulas, consider the estimate that 67.3% of the patients in Kampala claimed to know rights and mentioned at least one right. Applying B.1 we calculate the variance to be:

$$\text{var}(\hat{\theta}) = \frac{0.673 * 0.327}{902,900 - 1} * (1 - \frac{150}{902,900}) = 0.00147674 \quad 12$$

Where N=902,900 and n=150.

According to B.2, the confidence interval is then given by:

$$0.673 \pm 1.96\sqrt{0.0014767412} = \begin{cases} 0.598 \\ 0.748 \end{cases}$$

Where α=0.05.

In sum, the estimate of awareness of rights for Kampala falls between 59.8% and 74.8% with 95% confidence. This estimate therefore has an error margin of plus/minus 7.5 percentage points.

Similar confidence intervals have been calculated for key variables mentioned in the report using the above formulae. Generally, the error margin falls between a minimum of +/- 0.6 percentage points and a maximum of +/-8 percentage points, depending on the value of the estimate. An error margin of this size is quite typical for minor baseline surveys in Uganda. Error margins can be reduced, but at a considerable cost because the sample size must increase. Reducing the error margin to +/- 3 percentage points, for instance, would have seven-doubled the total costs of collecting the data, as illustrated in the table at the end of Appendix B.