COLLEGE OF MEDICINE AND HEALTH SCIENCES, SCHOOL OF MEDICINE AND
PHARMACY, DEPARTMENT OF SURGERY

# FACTORS AFFECTING QUALITY OF LIFE OF PATIENTS LIVING WITH STOMA IN A TERTIARY HOSPITAL IN RWANDA.

Dissertation submitted in partial fulfillment of the requirements for the award of the degree of
Master of Medicine in General surgery, University of RWANDA

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**AUGUST 1, 2021**

## DECLARATION

The researcher:

I Dr NIYONSHUTI Norbert hereby declare that this dissertation **"Factors affecting quality of life of patients living with stoma in a tertiary hospital in Rwanda"** is my own work and it has not been submitted by anyone to any other University for the award of a degree.

Signed: ……………………

Date29/08/2021

Dr. NIYONSHUTI Norbert

The supervisor:

I hereby declare that this dissertation **"Factors affecting quality of life of patients living with stoma in a tertiary hospital in Rwanda"** was submitted by Dr NIYONSHUTI Norbert with my approval.

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Prof NTIRENGANYA Faustin

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# DEDICATION

To God the Almighty

To my late Parents

To my Wife and Son

To my Brothers and Sisters

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## LIST OF ABBREVIATIONS

**APR**: Abdomino-Perineal Resection

**CBHI**: Community Based Health Insurance

**CHUB**: Centre Hospitalier Universitaire de Butare

**CHUK**: Centre Hospitalier Universitaire de Kigali

**LMICs**: Low and Middle Income Countries

**SF-36**: 36- Item Short-Form Health Survey

**SPSS**: Statistical Package for the Social Sciences

**COH-QOLOQ**: City of Hope Quality of Life-Ostomy Questionnaire

**QLI**: Quality of Life Index

**QoL**: Quality of life

**USA**: United State of American

**UR**: University of Rwanda

**WHO**: World Health Organization

# ABSTRACT

**Background:** A stoma is a surgical opening of the intestines through the abdominal wall. Quality of life (QoL) of patients with stomas constitutes a crucial public health challenge, generally in Low and Middle Income Countries (LMICs) and particularly in Rwanda.

**Objectives:** This study had objectives to describe demographic characteristics, determine health related QoL, identify modifiable factors influencing QoL of patients living with stoma and explore patient perceptions about stoma and stomatherapy.

**Methods:** This was a mixed-methods study with sequential explanatory design. 47 patients living with stoma have been included from January to June 2021. Demographics and other variables of interest were collected using a pre-established data collection sheet and QoL was assessed using Stoma QoL scale, a validated questionnaire for assessing health-related QoL of patients living with colostomy and ileostomy.

**Results:** 47 patients living with stoma and followed in the outpatient clinics of CHUK and CHUB were included in this study. 57.4% of them were male, 51.1% aged 50 years and above, 51% were in low socio-economic class (second category of ubudehe), 57.4% were farmers and 89.4% had community based health insurance (CBHI). The majority of patients were married (78.8%) and still leaving with their partners. 72.3% had a “poor /worst” quality of life, 27,7% had “good” quality of life and no one (0%) had “best” QoL according to Stoma Quality of life Scale classification. age (p-value=0.001), Type of stoma (p-value=0.017), duration of stoma (p-value= 0.017), socio-economic status (p-value=0.027), level of education (p-value=0.007), availability of stoma bag (p-value= 0.008), patient’s education after surgery (p-value= 0.005) have been identified as factors influencing QoL.

The main recurrent themes in qualitative analysis were “lack of special education and follow up near home for stoma therapy”, “stoma bags are neither available nor affordable” and “living with stigma in the society”.

**Conclusion:** The majority of patients followed for stoma in Rwanda tertiary hospitals have poor /worst quality of life. Addressing different challenges including affordability and accessibility of stoma bags, lack of community based follow up and poor patient education on stoma and stoma-therapy may improve the QoL of patients living with stoma.

**Key words**: stoma, quality of life, stoma care

# CHAPTER I: INTRODUCTION

## 1.1. Background

A stoma is a surgical opening of the intestines through the abdominal wall.(1)(2)(3) It is the most common life-saving surgical procedure performed in the treatment of acquired and congenital gastrointestinal diseases.(1) Intestinal stoma consists in elimination of feces and flatus via the intestinal part which is exteriorized to the abdominal wall.(4) There are various types of intestinal stoma depending on intestinal part exteriorized, the most common are colostomy and ileostomy. Each year in United States, around 100,000 patients undergo surgery which end up with stoma formation.(5)

Common indications of stoma creation are to divert stool flow, protect anastomotic site, and bowel decompression, in gastrointestinal conditions such as peritonitis secondary to typhoid perforation, colonic obstruction, trauma (injury by firearms and road trafficking accident), and inflammatory bowel diseases.(5)(6)

Despite that intestinal stoma is a life-saving procedure, it is associated with life style changes which may be a burden to the patient and affect negatively his quality of life (QoL).(7) The World Health Organization (WHO) explains (QoL) as personal impression in relation to their expectations and goals even in their position in life, in context of culture and value systems in which they live.(8) By WHO terms, QoL covers five dimensions: environment, social relationships psychological health, level of independence and physical health.(7)

Factors affecting the QoL of patients living with stoma include modifiable and non-modifiable factors such as age, sex, indication of stoma, duration of stoma, marital status, level of education, and type of stoma.(9)(10)Furthermore, education on stoma care before and after stoma creation has an impact on QoL of patient living with stoma.(4)

Unfortunately, there is paucity of data regarding QoL of patients living with stoma in both developed and underdeveloped countries. Particularly, patients living with stoma face many problems in Low and Middle Income Countries (LMICS). Identification of modifiable factors influencing QoL of patients living with stoma and explore patients perception about stoma and stomatherapy in Rwanda will contribute to their management for an appropriate decision-making and pre or post-operative planning in order to control disease, complications, thus, improve QoL of this particular group of patients.(11)

## 1.2. Problem Statement

Stoma creation is among the most lifesaving procedures performed in general surgery in tertiary hospital of Rwanda. In this regard, estimated incidence of patients living with stoma is rising with the growing number of surgeons and the complexity of procedures that can be performed in different hospitals.

While exploring records from Kigali university teaching hospital (CHUK) registry, we found that in a period of one year from January to December 2020, 61 procedures resulting in creation of ileostomy or colostomy were performed. Less than half of those patients underwent stoma closure. The remaining were either on pending list or they had permanent stoma.

During outpatient's consultation, those patients who stayed with stoma complained of inadequate education on stoma care by a medical personnel before and after surgery and lack of stoma bag at nearest health facilities and sometime even at CHUK. Their families were not aware on how stoma care is done properly. Most of them looked depressed, and they couldn't get easily a psychological support while in the hospital and even after discharge.
However, there is no documented data on QoL of those patients who stayed with stoma and no study was conducted to assess the health related QoL among patient living with stoma in Rwanda.

Based on studies conducted elsewhere, we hypothesize that the quality of life of patients living with stoma is seriously impaired and urgent remedial measures may be needed. In a review of Susanty S et al, 25% of stoma patients experienced depression, anxiety and negative emotions following stoma surgery, 50% were worried about their altered body image, 47% lost confidence, and 23% felt sexually altered and unattractive.(12)

## 1.3. Study justification

Quality of life data are useful in order to improve patients' experiences. Indeed, for a better QoL, patients living with stoma require a close follow up by a well-trained team (surgeon, nurses, entero stomal therapist) and special materials like stoma bag, skin barrier and adhesive product are needed for a better QoL.(4)
Different factors have been shown to influence quality of life of patients living with stoma. These factors include age, sex, level of education, type of stoma, cause of stoma, duration of stoma, marital status, indication of stoma.(9)(10)Furthermore, it has been shown that education on stoma care before and after stoma creation have an impact on QoL of patient

living with stoma.(4) However, no detailed analysis has been made to identify which of the above mentioned factors can be easily addressed (modifiable factors) to improve on short term the QoL of patients living with stoma generally in Africa and particularly in Rwanda.

Furthermore, identifying those factors which influence the quality of life may allow surgeons and the treating team in charge of patients with stoma to anticipate and develop clinical guidelines and follow up protocols and hence improve the quality of life of patients with stoma.(13)

Unfortunately, there is shortage of data on quality of life of patients living with stoma in our country. In our best knowledge, no single study has been conducted on the subject. Few studies available in the region are retrospective in nature and lack patients' perceptions. Since there is a lack of information about the quality of life and its influencing factors among patients living with stoma in Rwanda, it is important to bridge that gap.

Results from this study will contribute in guidelines and quality improvement projects, to be disseminated and implemented as part of routine clinical care. Furthermore, they may be used by health policy-makers to improve the QoL of patients living with stoma in Rwanda.

## 1.4. Research Question and Hypothesis

### 1.4.1. Research Question

What are the modifiable factors influencing Quality of life for patients living with stoma and how do patients perceive stoma care provided in tertiary hospitals in Rwanda?

### 1.4.2. Hypothesis

We hypothesized that non-availability of stoma bag, education before and after stoma creation are modifiable factors that may influence the Quality of life of patients living with stoma in Rwanda.

## 1.5. Objectives

### 1.5.1. General Objective

To investigate the quality of life of patients living with stoma

### 1.5.2. Specific Objective

1. To describe demographic characteristics of patients living with stoma

2. To determine health related quality of life of patient living with stoma using Stoma Care Quality of life Scale

3. To identify modifiable factors influencing Quality of life of patients living with stoma

4. To explore patient perception about stoma and stoma-therapy.

# CHAPTER II: LITERATURE REVIEW

## 2.1. Intestinal stoma

Intestinal stoma is a surgical exteriorization of a segment of bowel either small or larger bowel through the anterior abdominal wall.

Common intestinal stoma experienced in primary care are colostomies and ileostomies that can be temporary or permanent.(4)(14)

Generally, ileostomy is made by terminal ileum which can be an end or a loop stoma according on the indication.(15) Colostomy refers to exteriorization of any part of colons; currently colostomy is indicated in colonic obstruction (primarily due to cancer or volvulus), perforation with fecal peritonitis when anastomosis is not indicated, recto-vaginal fistulas and perianal sepsis.(15)

The creation of a stoma induces physical changes to patients' life in addition to significant stress related to the indication of stoma creation such as malignancy. Aside from physical change, a stoma also affects psychological and sexual health. Initial management of patients requiring intestinal stoma, should focus on clear explanation of stoma and its complications to provide appropriate care.(4)

## 2.2. Indications of intestinal stoma

The Major indications of intestinal stoma include diffuse bowel injury or obstruction which preclude primary anastomosis such as: longstanding peritonitis with peri-operative hemodynamic instability, colonic obstruction (primarily due to cancer or volvulus), trauma, irradiation damage, ischemia, bowel obstruction with gangrenous, ulcerative colitis, crohn's disease, and diverticular disease.(15)(16)

## 2.3. Classifications of intestinal stoma

Intestinal stoma is classified depending to the segment of bowel that is brought through the antero-lateral aspect of abdominal wall (ileostomy vs colostomy), the surgical technic (end stoma, loop stoma) and the duration of stoma.(17)

### 2.3.1. End stoma

The term end ileostomy or end colostomy is used after resection of segment of bowel, one part of bowel is brought out and connected to the abdominal wall to create a stoma, the remaining part is over-sewn. An end stoma can be temporary or permanent depending on their indications.(15)(17)

### 2.3.2. Loop stoma

Loop stoma is created when the distal bowel is not well functioning. A loop of intestine is exteriorized and connected to the abdominal wall.(14)

Technically, the loop of bowel is partially opened with the edges, then folded back and fixed to the skin with absorbable sutures thus creating two opening, whereas the distal one is for mucus discharge and proximal for feces. During formation of loop some anatomical considerations are needed, a loop stoma is created to the segment of intestine which have a mesentery or mesocolon that will allow the intestine to reach easily the surface of abdominal wall. Most of the time loop stoma is temporary.(14)(17)

### 2.3.3. Double – barreled stoma

A double-barreled stoma is created after resection of intestine and both end of intestine is brought through the abdominal wall. In contrast to loop stoma both ends are not connected but are exteriorized through the same defect.(14)(17)

### 2.3.4. Divided or split stoma

Divided stoma is type of stoma when both limbs of divided intestine are exteriorized to the abdominal surface, but through two different stoma site. Split stoma is indicated in case of subtotal colectomy which end up by creation of ileostomy and colostomy made by rectum works as mucus fistula. Generally is temporary in nature.(15)

### 2.3.5. Temporary or Permanent intestinal stoma

#### 2.3.5.1. Temporary stoma

A temporary stoma is created to try to control septic complications from anastomotic breakdown and to avoid the need for reoperation. Therefore, in case of surgery done on unstable patients where the breakdown of anastomosis is possible due to the status of patient. The reversal of temporary stoma is then planed depending on status of patient and once acute medical condition has improved.(18)(15)

Generally, a temporary stoma reversal should occur not less than 8 to 12 weeks after the initial operation when the inflammation of stoma has resolved and the intra-abdominal adhesions are more manageable.(18)

#### 2.3.5.2. Permanent stoma

Permanent stoma is indicated when there are no options to take down the stoma created depending on primary indications, for example in case of rectal tumor managed with abdomino-perineal resection (APR) or once the indications is for palliation in case of tumor which is not respectable and they are need of stoma to divert intestine content.(17)

## 2.4. Physiological aspect of intestinal stoma

The creation of stoma is linked with changes in the physiology of the gastro intestinal tract where there is a reduced resorption part of intestine.

Resorption part of intestine is interrupted in small intestine stoma, but also in case of stoma made on proximal colon, this interruption may lead to dehydrations and electrolytes imbalances.(17)

Every day 1500 to 2000 ml of enteric content passes through ileocecal junction. While passing through the large intestine around 90% of this amount is resorbed.(17)The absence of the resorption area of the colon after formation of ileostomy may cause dehydration.(19)

Physiologically, nutritional disorders will depend on segment of the small bowel that has been bypassed or resected. For stoma made at the level of colon the physiological change is linked to the remaining absorptive part of colon.(17)

## 2.5. Stoma complications

Twenty to forty percent of patients with stoma have complications.(20)(15)

Those complications depend on surgical site selection and stoma construction. It has been proven that some comorbidities predispose to complications such as smoking and obesity.(20)

Complications related to stoma may classified as early complications (stoma necrosis, infection. Dehiscence and stoma retraction) and later complications (stoma stenosis, obstruction, parastomal hernia, prolapse, and fistula formation). In additional at any time bleeding, skin excoriation and high stoma output may occur as a complication of stoma.(20)

## 2.6. Stoma care

After surgery, Stoma care is crucial. It is done in hospital during hospitalization and even after discharge. It has been shown that improper management of stoma decrease QoL of patient living with stoma.(21)(22) Stoma care includes assessing complications related to stoma by examining its viability and functioning, teaching patients about stoma hygiene, how to change stoma bags and to look for complications. (22)

After discharge, follow up of patients living with stoma done by entero-stomal therapists in contact with surgeons has shown to offer appropriate management, anticipate complications and improve patients' quality of life.(23)(22)(21)(22)

In addition to healthcare professionals in stoma care, materials are also needed for stoma care and prevention of related complications.(4)(16) These include stoma bags, hyperosmotic agents like glycerin, skin barrier products (tube paste, powder or ling), and adhesive products that increase the stickiness between the pouching system and skin, in form of cement or spray. (16)(24)

### 2.7. Professionals involved in patients living with stoma care

Stoma changes life style of patient dramatically. Several publications shown that stoma is linked with deterioration of QoL of patients living with stoma.(17) Consequently, proper stoma care is very crucial and several medical professionals should be involved in the management of patients with stoma. Ideally, patient will be seen by a stomal therapy nurse pre-operatively even post operatively for education on stoma and to mark stoma site.(20) In emergency conditions, patient may not be seen by a stomal therapy nurse pre-operatively.

After surgery, Stomal therapy nurses should provide patient education and support, selecting appropriate stoma bags, assessing stoma problems to optimize physical and psychological wellbeing.(25) A general practitioner and a stomal therapy nurse are the one who firstly assess patient with stoma and they will managed according to the status and complications related to stoma.(20)

In the management of patients with stoma surgeon assess patient pre operatively during decision making, early post-operative period even at the time of stoma reversal, further stoma care is done by stomatherapist who involve surgeon in case of complications.

### 2.8. Tools for measuring quality of life

Varies tools have been developed to assessing QoL. There are general tools that can be used to different disciplines such as 36- Item Short-Form Health Survey (SF-36) and others specifically designed for patients living with stoma (ileostomy, urostomy and colostomy).(26) These tools include City of Hope Quality of Life-Ostomy Questionnaire (COH-QOLOQ)(27), and the Stoma Care Quality of Life Index constructed as a modification of "QLI" designed for cancer patients.(23)(28)

Stoma Quality of life scale is a validated questionnaire for assessing health-related quality of life of patients living with colostomy and ileostomy. It is designed with 20 items that covers four domains – sexual activity, sleep, relations to family and close friends, and social relations to other than family and close friends.(23)(28)(29)

### 2.9. Factors influencing QoL of patients living with stoma

Many factors have been shown to influence the quality of life of patients living with stoma in multiple studies done previously, found that age, income, gender to be the main factors affecting quality of life of patients with stoma.(26) Different studies shown that women has poor quality of life than men in overall domain such as studies conducted in Germany,(30) Turkey.(8) Another study done by Chunli L. et al found that overall QoL was influenced by duration of stoma, hope, and skills. For work and social function were influenced by sex, education, and skills. Sexuality and body image was influenced by knowledge. The variables influencing stoma function were sex, complications related to stoma, level of education, skills and knowledge.(8)

Also education before and after stoma creation is one of the modifiable factors which influence QoL of patients living with stoma but if there is a lack of stomatherapist then the education done is not satisfactory.(4)(24) And it has been shown that in western country where the stomatherapist nurses are available the QoL is better than in low income country.(6)

This can be explained by the fact that the stoma patient may undergo stoma creation without knowing what is stoma, what challenges he or she will be facing in coming days, like daily stoma care, travel limitation, lack of acceptance in society and in body image. That is why preoperative and post-operative education done properly and postoperative to patients and their families are crucial to address various problems including psychosocial and economies aspect.(6)(31)

Stoma bag is a modifiable factors influencing QoL of patient living with stoma, it has been published that the lack of stoma bag and bad quality of stoma bag may affect dramatically the QoL of patient living with stoma due to leakage of stoma effluent, and also lack of stoma bag may results in contact of stoma effluent to the peri-stoma skin, potentially causing irritation of the skin which will affect negatively the QoL of patient living with stoma.(32)

To improve availability of good quality stoma bags for every stoma patient is one of the most strategies can be taken in consolidation during stoma care to improve the QoL of stoma patient.(32)

# CHAPTER III: METHODS

## 3.1. Study design

This was a Mixed-methods study with sequential explanatory design

## 3.2. Study site

This study was conducted at the University Teaching Hospital of Kigali (CHUK) and the University Teaching Hospital of Butare (CHUB).

CHUB and CHUK are tertiary public hospitals in Rwanda. CHUK is located in Kigali the capital city (District of Nyarugenge). CHUK has a capacity of 560 beds with 25% allocated to the department of surgery. Department of surgery is composed by nine specialties (General surgery, Plastic surgery, Orthopedic surgery, Neurosurgery, Urology, Pediatric surgery, oral & maxillofacial, Ophthalmology and ENT surgery).

CHUB is located the Southern Province. It has capacity of 500 beds with 122 beds allocated to the department of surgery, the department of surgery has four specialties (General surgery, Orthopedic surgery, Urology and ENT surgery).

## 3.3. Study population

Patient living with stoma aged 18 years old and above, who came as outpatient in general surgery units at CHUK and CHUB for follow up, having an ostomy in place for at least 1 month after hospital discharge.

## 3.4. Selection of study population

### 3.4.1. Inclusion criteria

Age: >18 years' old

Having a stoma in place for at least 1 month after hospital discharge

### 3.4.2. Exclusion criteria

Patient with mental illness, those who are on medications or followed by psychiatrist before stoma

### 3.4.3. Sampling

This study used a convenience sampling.

For quantitative phase, all patients living with stoma aged 18 years old and above, who came as outpatient in general surgery units at CHUK and CHUB for follow up, having an ostomy in place for at least 1 month after hospital discharge have been included for 1 year period,50 patients having stoma have been identified. all of them met our inclusion criteria. 3 patients have been excluded and 47 considered for the final analysis.

For qualitative phase, a purposive sampling was used and 20 participants have been interviewed before reaching saturation.

## 3.5. Data collection and variables

### 3.5.1. Data collection and analysis

**Data was collected in 2 phases:**

**Quantitative data**: In our study, we enrolled patients living with stoma consulting at CHUK, CHUB in outpatient clinic one month after discharge. Patients who meet inclusion criteria signed a consent form and data were collected using a pre-established questionnaire together with stoma care QoL Questionnaire. Demographic, clinical, life style and quality of life data were collected (Annex 1).

The Stoma QoL Questionnaire was particularly designed to assess stoma-specific QoL with 20 items that focus on factors directly related to QoL of patients living with a stoma. Participants responded to each of the 20 items on a 4-point scale with numbers referring to; 1 = always, 2 = Some times, 3 = rarely & 4 = Not at all.(8)

The Stoma QoL score was calculated as a proportion of the total sum of a participant's responses and the highest possible sum is 80.

The sample's overall Stoma-related QoL was presented as the mean of the individual scores. Stoma-related QoL scores were classified as best (>70), good (51 – 70), poor (31 – 50) and worst (≤ 30).(23)(29)

Demographic and Clinical data collected included age, gender, level of education, cause of stoma (malignant or benign), context of surgery (emergency or elective), type of intestinal stoma (colostomy, ileostomy), duration of stoma, availability of stoma bag, education before and after stoma creation etc. (Annex 1)

Data were entered using EpiData 3.1 software, then imported into SPSS version 24.0 for data analysis. Before data analysis, imported data were cleaned for errors or omissions. After data cleaning, descriptive statistics were performed for sociodemographic characteristics of participants, quality of life score, indications of stoma and encountered stoma complications. For factors influencing quality of life among patients, median quality of life score was determined and used to compare score between groups of independent sample. To determine significant factors, non-parametric test (Mann-Whitney U test) was performed and p-value less than 0.05 were considered as statistically significant.

**Qualitative data**: Based on quantitative results, a qualitative questionnaire was developed. The purposive sampling was used and 20 participants have been interviewed.

Qualitative data were collected using semi-structured interviews. Thematic analysis was conducted. Information and opinions collected from interviewees were recorded into transcripts in Kinyarwanda then translated in English. Then, the transcripts were explored and reviewed several times to create initial codes according to our study objectives. A codebook was developed to facilitate interpretation of responses provided by participants then quotes from same themes and subthemes were assigned the same codes. The coding and analysis of the data were done using “Atlas.ti” software version 7.1.4

### 3.5.2. Variables

Different variables were obtained from electronic file in outpatient clinic and from direct interview with patients. (Annex 1)

## 3.6. Data security

Locked cabinets were used to store all paper-based study data and were only be accessed by the study team, the principal investigator was in charge of the data security.

The electronically generated data was protected with password and only the principal investigator was having access to it.

## 3.7. Ethical Considerations

The research proposal has been approved by the Department of Surgery/UR. It has been evaluated and approved by the Institutional Review Board (IRB) of the University of Rwanda, The College of Medicine and Health Sciences. Prior to data collection, additional respective ethical clearances have been obtained from respective research hospitals (CHUK and CHUB).

An informed consent has been obtained from the patient. The information obtained has been treated confidentially, and only used for research purposes.

### 3.8. Conflict of interest

The authors declare no conflict of interest

## CHAPTER IV: RESULTS

Forty-seven patients living with stoma followed in outpatient department of general surgery at CHUK and CHUB have been included in the study.

### 4.1. Sociodemographic characteristic of patients living with stoma

**Table 1 : Sociodemographic characteristic of patients living with stoma**

| Variable | category | Count | Percentage |
|---|---|---|---|
| AGE GROUP | <50 | 23 | 48.9 |
| | >50 | 24 | 51.1 |
| GENDER | Male | 27 | 57.4 |
| | Female | 20 | 42.6 |
| UBUDEHE | Cat I | 6 | 12.8 |
| | Cat II | 24 | 51.1 |
| | Cat III | 17 | 36.2 |
| INSURANCE | CBHI | 42 | 89.4 |
| | Private | 5 | 10.6 |
| EDUCATION | None | 21 | 44.7 |
| | Primary | 16 | 34.0 |
| | Secondary | 7 | 14.9 |
| | University | 3 | 6.4 |
| OCCUPATION BEFORE | Farmer | 27 | 57.4 |
| | Paid job | 6 | 12.8 |
| | Private job | 5 | 10.6 |
| | None | 9 | 19.1 |
| OCUPATION AFTER | farmer | 7 | 14.9 |
| | Paid job | 4 | 8.5 |
| | Private job | 1 | 2.1 |
| | None | 35 | 74.4 |
| Marital before | Single | 3 | 6.4 |
| | Married | 37 | 78.7 |
| | Divorced | 1 | 2.1 |

|  |  |  |  |
|---|---|---|---|
|  | Widowed | 5 | 10.6 |
|  | Separated | 1 | 2.1 |
|  | Single | 3 | 6.4 |
|  | Married | 36 | 76.6 |
| Marital after | Divorced | 1 | 2.1 |
|  | Widowed | 5 | 10.6 |
|  | Separated | 2 | 4.3 |

**#Ubudehe category**: economic life standing of households of Rwandan population

# **CBHI**: Community Based Health Insurance

Table 1 shows that patients living with stoma were nearly equally distributed among both age groups where 48.9 % were below 50 years old and 51.1% were above 50 years. Majority of study participants were male (57.4%), in second category of UBUDEHE (51%), and using CBHI (89.4%). Regarding education level, majority of patients did not attend any formal education, and 57.4% were farmers and 78.8% were married.

### 4.2. Quality of life of patients living with stoma

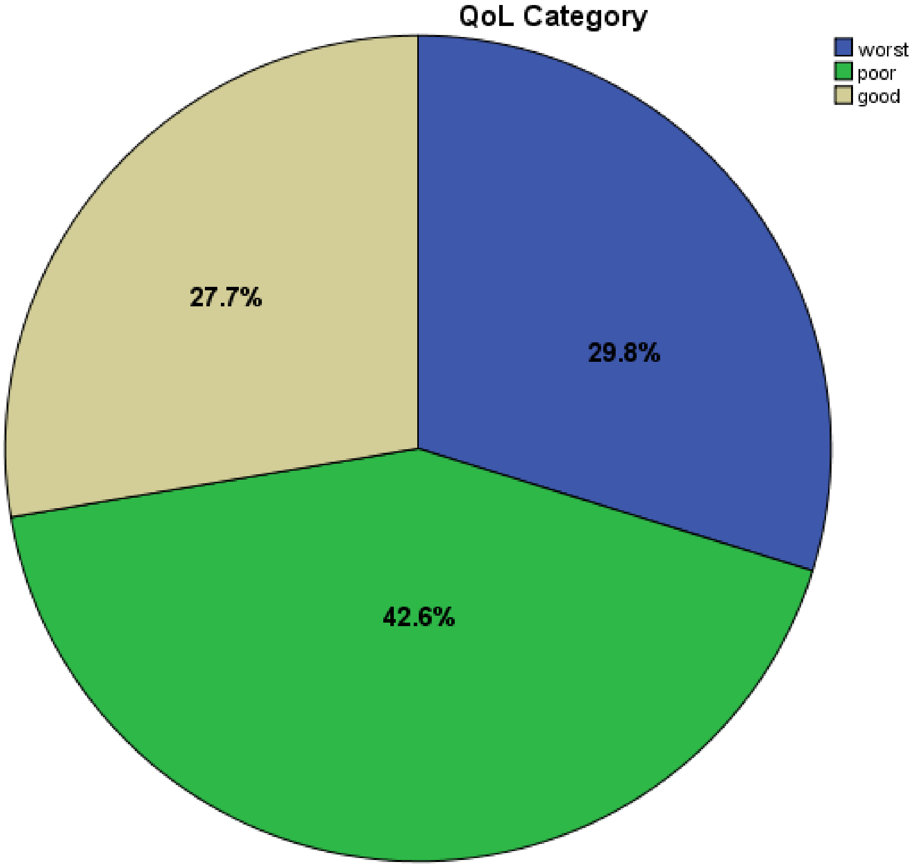
**Table 2 : Quality of life of patients living with stoma**

| QoL indicators | Possible max score | Median score |
|---|---|---|
| Stoma device function | 12 | 5 |
| Self-esteem and self-image | 20 | 10 |
| Sleep and fatigue | 12 | 6 |
| Family and friends | 36 | 16 |
| Overall QoL score | 80 | 38 |

**#QoL:** Quality of Life

Table 2 shows that overall median quality of life was below half of total overall score which indicates the bad quality of life for patients with stoma. For Stoma device function, self-esteem & self-image, sleep & fatigue and family & fiends scores, their median quality of scores were not above half total quality score which indicate the bad quality of life for all assessed indicators.

## 4.3.Distribution into different Categories of quality of life



**#Stoma-related QoL scores= Best: (>70), Good: (51 – 70), Poor: (31 – 50) and Worst: (≤ 30)**

**Figure 1: Category of quality of life among patient with stoma**

Figure 1 shows that majority of patients had poor or worst quality of life (cumulatively 72.3%) and only few people experienced good quality of life (27.7%). No one experienced best quality of life indicated by QoL score above 70.

### 4.4. Factors influencing quality of life among patients with stoma

**Table 3: Factors influencing quality of life among patients with stoma**

| **Variable** | **Device Function score** | | **Self-Esteem &image score** | | **Sleep &fatigue score** | | **Family & friends score** | | **Overall score** | |
|---|---|---|---|---|---|---|---|---|---|---|
| | **Median** | **p-value** | **Median** | **p-value** | **Median** | **p-value** | **Median** | **p-value** | **Median** | **p-value** |
| **Gender** | | 0.817 | | 0.488 | | 0.686 | | 0.258 | | 0.458 |
| Male | 5 | | 11 | | 6 | | 18 | | 39 | |
| Female | 5 | | 9 | | 5.5 | | 16 | | 35 | |
| **Age group** | | **0.031** | | **0.001** | | **0.043** | | **<0.001** | | **<0.001** |
| <50 | 4 | | 7 | | 5 | | 14 | | 30 | |
| >50 | 5 | | 13 | | 7 | | 23 | | 51 | |
| **Insurance** | | 0.034 | | 0.215 | | 0.535 | | 0.449 | | 0.202 |
| CBHI | 5 | | 10.5 | | 6 | | 16.5 | | 38.5 | |
| Private | 3 | | 8 | | 6 | | 14 | | 34 | |
| **Ubudehe** | | 0.444 | | **0.009** | | 0.082 | | 0.340 | | 0.020 |
| Cat I | 4.5 | | 6 | | 5 | | 15 | | 29.5 | |
| Cat II/III | 5 | | 11 | | 6 | | 17 | | 40 | |
| **Education** | | 0.052 | | **0.030** | | 0.117 | | **0.003** | | **0.007** |

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| None/primary | 5 | | 11 | | 6 | | 17 | | 40 | |
| Secondary/university | 3 | | 6 | | 5 | | 14 | | 29 | |
| **Occupation before** | | **0.035** | | 0.081 | | 0.182 | | 0.199 | | 0.095 |
| Paying occupation | 3 | | 6 | | 6 | | 14 | | 32 | |
| Not paying | 5 | | 4.5 | | 6.5 | | 17 | | 40.5 | |
| **Occupation after** | | 0.580 | | 0.802 | | 0.651 | | 0.987 | | 0.854 |
| Paying occupation | 4 | | 11.5 | | 6 | | 17 | | 38 | |
| Not paying | 5 | | 10 | | 6 | | 16 | | 38 | |
| **Marital status before** | | 0.144 | | **0.046** | | 0.117 | | 0.636 | | 0.070 |
| Living with partner | 5 | | 11 | | 6 | | 16 | | 40 | |
| No partner | 3 | | 6.5 | | 5 | | 16.5 | | 31.5 | |
| **Marital status after** | | 0.199 | | **0.012** | | 0.068 | | 0.495 | | **0.037** |
| Living with partner | 5 | | 11.5 | | 6 | | 16.5 | | 40 | |
| No partner | 3 | | 6 | | 5 | | 16 | | 31 | |
| **Weight gain** | | 0.281 | | 0.758 | | 0.058 | | **0.005** | | **0.031** |
| Gain | 5 | | 12 | | 7 | | 21 | | 47 | |
| loss | 4.5 | | 9.5 | | 6 | | 14 | | 32.5 | |

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| **Duration of stoma** | | **0.026** | | **0.005** | | **0.028** | | **0.021** | | **0.017** |
| <6months | 5 | | 13 | | 8 | | 21 | | 47 | |
| >6 months | 4 | | 7 | | 7 | | 14.5 | | 33 | |
| **Type of stoma** | | 0.562 | | 0.201 | | **0.023** | | **0.049** | | **0.027** |
| Ileostomy | 4.5 | | 8.5 | | 5 | | 15.5 | | 31 | |
| Colostomy | 5 | | 12 | | 7 | | 21 | | 42 | |
| **Class of stoma** | | **0.046** | | 0.175 | | 0.642 | | 0.549 | | 0.604 |
| Temporary | 5 | | 11.5 | | 6 | | 16 | | 38.5 | |
| Permanent | 4 | | 8 | | 6 | | 18 | | 36 | |
| **Surgery type** | | 0.491 | | 0.375 | | 0.952 | | 0.329 | | 0.924 |
| elective | 4 | | 9 | | 6 | | 18 | | 38 | |
| emergency | 5 | | 11 | | 6 | | 15.5 | | 38 | |
| **Primary disease** | | 0.115 | | 0.102 | | 0.225 | | 0.845 | | 0.277 |
| Malignant | 4 | | 7.5 | | 5.5 | | 17.5 | | 34 | |
| Benign | 5 | | 12 | | 6 | | 16 | | 39 | |

Table 3 Indicates that device function-related quality of life were influenced by age, insurance, occupation prior stoma, stoma duration and class of stoma. Median quality of life for device function is higher in patients above 50 years than it is in patients below 50 years. A higher median score was found in patients with CBHI insurance (p=0.031), patients with non-paying job (p=0.035), patients with stoma lasting less than 6 months (p=0.026) and with temporary stoma (p=0.046).

Self-esteem and self-image-related quality of life is influenced by age, ubudehe category, education level, marital status before stoma and after and duration of stoma. The higher median quality of score was found in patients above 50 year old (p=0.001), patients in 2nd and 3rd ubudehe category (p=0.009), patients who did not attend any formal education or attended primary only (p=0.030), patients living with their partner before (p=0.046) and after stoma (p=0.012) and for patients with stoma lasting less than 6 months (p=0.005).

Fatigue and sleep-related quality of life score was influenced by age, stoma duration and type of stoma. The higher median quality of life concerning fatigue and sleep was in patients above 50 years (p=0.043), in patients with stoma of less than 6 months (p=0.028), and in patients with colostomy (p=0.023) than in patients below 50 years old, patients with stoma lasting more than 6 months and patients with ileostomy respectively.

Family and friend related quality of life score is affected by age, education level, weight gain after stoma, stoma duration and type of stoma. The higher median quality of life score concerning family and friend was found from patients above 50 year old (p<0.001), in patients who did not attend any formal education or attended primary only (p=0.003), patients who gained weight after stoma (p=0.005), patients with stoma lasting less than 6 months (p=0.021) and patients with colostomy (p=0.049) than in people below 50 year old, patients attend secondary or university, patients who lost weight after stoma, patients with stoma of more than 6 months and patients with ileostomy respectively.

Overall quality of life score for patients with stoma is affected by age, education level, marital status after stoma, weight gain after stoma, stoma duration and type. Median overall quality of life score was higher in patients aged above 50 year old (p<0.001), patients who did not attend any formal education or attended only primary (p=0.007), patients living with their partners after stoma (p=0.037), weight gain after stoma (p=0.031) , patients with stoma of less than 6 months (p=0.017) and patients with colostomy(0.027) than in people below 50 year old, patients who attended secondary or university, patients not living with their partners after stoma, patients who lost weight after stoma, patients with stoma of more 6 months and patients with ileostomy respectively.

### 4.5. Modifiable factors influencing quality of life among patients with stoma

**Table 4: Modifiable factors influencing quality of life among patients with stoma**

Table 4 shows that availability of stoma bags affects sleep and fatigue score (p=0.009), family & friends score (p=0.034) and overall QoL score (p=0.008) and education before stoma affects sleep and fatigue score (p=0.049) while education after stoma affects all

| **Variable** | **Device Function score** | | **Self-Esteem &image score** | | **Sleep &fatigue score** | | **Family & friends score** | | **Overall score** | |
|---|---|---|---|---|---|---|---|---|---|---|
| | **Median** | **p-value** | **Median** | **p-value** | **Median** | **p-value** | **Median** | **p-value** | **Median** | **p-value** |
| **Availability of bag** | | 0.082 | | 0.094 | | **0.009** | | **0.034** | | **0.008** |
| **Yes** | 5 | | 12.5 | | 7.5 | | 20 | | 52 | |
| **No** | 5 | | 9 | | 6 | | 16 | | 34 | |
| **Education before stoma** | | 0.147 | | 0.180 | | **0.049** | | 0.340 | | 0.150 |
| **Yes** | 5 | | 12 | | 7.5 | | 27 | | 54.25 | |
| **No** | 4 | | 9 | | 6 | | 22 | | 49 | |
| **Education after stoma** | | **0.032** | | **0.028** | | **0.011** | | **0.012** | | **0.005** |
| **Yes** | 5 | | 12.5 | | 8 | | 15 | | 50 | |
| **No** | 4 | | 8 | | 6 | | 12 | | 32 | |

components of stoma QoLscore which are device function score (p=0.032), self-esteem & image score (p=0.028), sleep and fatigue score (p=0.011), family & friends(p=0.012) and overall score (p=0.005).

### 4.6. Participants perceptions on overall quality of life, identified factors influencing it.

Majority of patients expressed that they are not happy living with a stoma. They suggested that it would improve quality of life and minimize stoma related complications if there was someone to follow them up on regular basis and provide advices when needed.

“I have no stoma therapist. If I get one, he/she would help me understand the complications and solve some without the need of consulting at the hospital always” [Participant 12]

“I have no special follow up for stoma. What I think he/she would help is to direct me how to live with stoma and avoid complications” [Participant 13]

“I have no special person for stoma therapy. I think if I can get a stoma therapist they would help with stoma care and resolving complications by the time I am not able to reach the surgeon on an appointment” [Participant 16]

Other participants mentioned that they are followed by the surgeons who operated on them but they mentioned that they do not have regular follow up but only when they got complications. Few participants mentioned that they are followed at the nearest district hospitals.

“It is the doctor who operated on me but he is not always available for regular follow up, he can help me once complications happen.” [Participant 20]

“The follow up is done by the doctor who operated on me, but he can help me once I have complications……” [Participant 8]

One participant mentioned that it can help him if he is referred to the nearest hospital for stoma follow up because of financial difficulties.

“Stoma therapy is done by my doctor who operated me, but what he can do to improve my quality of life is to help me to continue follow up at nearest hospital if they are able to provide the same management to me because is very difficult for me to get the ticket” [Participant 4]

## 4.7. Participants perceived challenges

Many participants mentioned different challenge related to stoma usage. They include lack of stoma bags of good quality, stoma that stay for long because of lack of means to change them regularly. However, some of them highlighted poor knowledge about stoma related complications and lack of training in changing the bags.

“The challenge I have is how to get stoma bags, how to use those bags because sometimes we buy different types of stoma bags” [Participant 2]

“I don’t know why, but most of time when apply them, they are oozing and my skin get irritated” [Participant 12]

“Stoma bags remove themselves…. they don’t have gas filter and I sell not good when I’m in the public. So, I prefer staying home every time. …. When I’m asleep bags tend to remove themselves and dirty the bed… They are of poor quality” [Participant 15]

“It feels uncomfortable and causes some itching around. It sometimes removes itself and I don’t have enough money to keep replacing them” [Participant 17]

Participants mentioned that availability of bags of good quality, getting stoma bags in the nearest private dispensary pharmacies, nearest district hospitals and health centers, affordability of stoma bags and education on how to use the stoma bags can solve the challenges they have on applying and changing stoma bags.

“Avail good quality stoma bags in private pharmacies and if possible stoma bags should not be charged any money” [Participant 11]

“If we have like some association which can provide the stoma bag of good quality, on low cost will help much” [Participant 10]

“The only solution is to get affordable stoma bag in our hospital and get a different type that I am not allergic to” [Participant 19]

Participants expressed change in their daily living conditions because of being on stoma therapy where some mentioned emotions related to bad self-esteem, anxiety and self-discrimination in the society. Participants mentioned about being a burden to their families, lack of occupation, fear of being embarrassed in the public, avoiding sexual relations and lack of sexual desire and obligation to change the dressing style.

"…living with stoma is very challenging because I feel like I m a burden to my family, for example now I have no job because of stoma…." [Participant 10]

"I avoid going in public for the worry of stoma bad smell. I try not to have sexual relations with my wife because I fear the stoma might remove itself and embarrass me" [Participant 11]

"It feels uncomfortable to walk around with stoma. I have stopped doing sports and going to work for the fear it removes itself. I also don't feel comfortable going in gatherings" [Participant 17]

Participants mentioned the need of psychological management, support and follow up while using stoma to enhance self-acceptance, to prevent anxiety and depression and special education on their behavior change.

"We need the counselors to encourage self-acceptance and fight the anxiety" [Participant 13]

"I would like to have someone to comfort me and give me hope for life and also doctors may follow me up closely that the stoma gets closed as soon as possible" [Participant 16]

"We need to get good quality stoma bags and to get mental health support to improve our living style" [Participant 15]

"The patient and caregivers need a counselor for accepting the stoma. The patient with stoma should be received first to avoid the discomfort of sitting long with people" [Participant 15]

In addition to the need of psychological management, the participants mentioned the psychological support should be given as group therapy so that they can share experience among themselves.

“I would propose a daily caregiver and group therapy of patients living with stoma for it can help to improve the quality of live” [Participant 13]

“If we could get a group therapy of patients with stoma, it would help us share our experiences and how to overcome challenges” [Participant 15]

“Group therapy with a psychiatrist to help fight the anxiety and encourage self-acceptance” [Participant 17]

Participants expressed that there is a need of skilled personnel with enough knowledge on stoma and stoma bags at the level of district hospital and health center to help them in case of need or complications.

“My advice is to have someone in all district hospitals have someone with enough skills on stoma to help us to avoid complications related to stoma care which is not done properly because sometimes I buy stoma bag and I find that even the pharmacist doesn’t know how we use it.” [Participant 5]

“My advice is to have someone in all health centers that have some skills on stoma therapy” [Participant 10]

### 4.8. Education and information to be provided to patients with stoma

Some participants suggested that patients who necessitate stoma therapy should get enough information prior to surgery and that their families should get special education and counselling, proper education on nutrition, stoma care and frequency in changing the stoma bags in order to avoid complications.

“I and my family need the education about my health and explanations on what led doctors to give me stoma. Education on nutrition, proper stoma care and to know time limit the stoma bag should last” [Participant 16]

“To get information on how long the stoma will last and materials needed to take care of it, as well us how the stoma care is done” [Participant 15]

“We need to know where we can found stoma bag, and how we use it. And also we need to know what we can do to avoid complications” [Participant 9]

Some participants mentioned that they need to have explanations and information that they should need to have stoma after surgery so that they can be mentally prepared and be informed on the expected duration of stoma therapy.

“The doctor must explain why they are going to create a stoma for example me I knew that they created a stoma after recovery once a saw stool in the bed:” [Participant 10]

“We need much information about stoma before surgery and if there are some alternative treatment” [Participant 12]

“Before stoma creation we need clear information about our disease and why stoma is the only solutions” [Participant 19]

## CHAPTER V: DISCUSSION

In this study we aimed to describe demographic characteristics, determine health related QoL, identify modifiable factors influencing QoL of patients living with stoma and explore patient perception about stoma and stomatherapy. Forty-seven patients living with stoma and followed in outpatient clinics of general surgery at CHUK and CHUB were included into a quantitative analysis and twenty interviews were conducted before reaching the saturation point.

The Stoma QoL score was calculated as a proportion of the total sum of participant's responses with a highest possible sum of 80. The sample's overall Stoma-related QoL was presented as the mean of the individual scores. Stoma-related QoL scores were classified as; best (>70), good (51 – 70), poor (31 – 50) and worst (≤ 30).(23)(29)

In our study, the overall median quality of life score was 38 which indicate an overall poor quality of life. Indeed, 73% of our patients had poor or worst quality of life and no one had quality of life classified as best. Findings from studies done in LMICs were relatively similar. Ssewanya et al in Uganda found that 76% feel that their quality of life was sub-optimal.(29) However, Jayarajah et al evaluating the quality of life in patients with ostomies in Sri Lanka found the mean overall quality of life score of 53.07 ± SD 12.68.(10)

The overall quality of life of study participants from developed countries is high. For example, Chunli et al in China found a satisfactory quality of life of their patient with a mean QoL score of 56 ± 17. (33) The study done in USA by Janet et al showed that quality of life was good with mean score of 59.9±9.9. (34) This low score found in our study could be explained by a limited understanding of stoma in our population and non-availability of stoma devices. The poor socioeconomic status of developing countries also reflects on reduced quality of life of patient living with stoma in those countries

In this study, participants aged 50 years and above had good quality of life compared to patients below 50 years. They had a better device function-related quality of life, self-esteem and self-image quality of life. In contrast, there was no significant difference of quality of life score between age group. Janet et al in USA(33) and Silva J. et al in Portugal(8) findings. The exact cause of poor quality of life in young people found in our study is not clear, but the lack of materials used for stoma care in our settings and the fact that young people tend to be more affected with their physical appearance through hygiene could explain the poor quality of life score in patients under 50 years old.

Globally economic status affects the quality of life of patients living with stoma. Anecdotally, in our study, participants in lower economic categories showed had high scores especially in regard with self-esteem and self-image item and overall score of quality of life. These results were in contrast with findings from other studies.(34)(26)(35) As suggested by Coons et.al, the cost of stoma bag may affect the quality of life for stoma patients.(36)

In the current study, we found that the time length of living with stoma influenced the quality of life in all aspects namely device function quality of life, self-esteem and self-image quality of life, family and friends' related quality of life and the overall quality of life. We found that participants who lived with stoma for less than six months' period had a median score of 47, whereas those who lived with stomas for more than six months' period median score of 33 with P-value of 0.017. In contrast, a study done in Iran by Anaraki et al showed that it took at least a half year to feel comfortable with the daily care of stoma and diet.(37) Our findings reflect the poor long-term follow up of patients who are or expected to be on stomatherapy and the insufficient materials for stoma care.

In our study, we found that patients with colostomy scored significantly higher in overall QoL than patients with ileostomy (p value=0.027). In contrast, Silva et al in Portugal found no significant difference on overall QoL score between patients with colostomy and ileostomy.(8) Our results are similar to the results from Sultan et al study where they found that patients with colostomy score significantly higher compared to patients with ileostomy (p-value <0.0001).(38) Therefore, the higher score of patients living with colostomy could be related to the fact that effluents of colostomy might have less complications on skin, have less impact on personal hygiene and are easier to handle in case of lack of materials for stoma care.

We did not identify difference in quality of life score across gender groups, similarly to Silva et al study and Ssewanyana et al in Uganda.(8)(29). In contrast, Kement. et al in Turkey showed that women score worse in quality of life score compared to men.(39) Another study done in USA by Janet et al found that women had poor quality of life compare to men (P=0.0059).(33) There is no clear explanation of our results regarding QoL across gender group. A study on a bigger population with a more balanced ratio between women and men is needed for more clarifications.

Our results showed that education after stoma affects all components of stoma QoL score which are device function score (p=0.032), self-esteem & image score (p=0.028), sleep and fatigue score (p=0.011), family & friends (p=0.012) and overall score (p=0.005). The results were consistent with the results from the study done in New Delhi by Pradeep et al. who mentioned the efficacy of post-surgery counselling in multiple sessions in improving the quality of life.(23)

Our results revealed that the availability of stoma bags affects sleep and fatigue score (p=0.009), family & friends score (p=0.034) and overall QoL score (p=0.008). Those results are similar to Roshine et al findings in India where the majority of patients had impaired QoL. They reported that the cost of stoma care including stoma bag has caused further financial burden which impairs their QoL.(13)

Through their interviews, the majority of patients living with stoma expressed that they don’t have any special follow up for stoma therapy in their daily life. They suggested having someone to follow them. Follow up would minimize complications related to stoma and improve their quality of life as suggested by other studies.(24)(40)(22)(21) Jennie et al showed that with appropriate patients education and support, good quality of life is achievable.(24) This reflects the need of a special program to train health care providers on stoma therapy.

Our study participants expressed that they face different challenges that are related to stoma and stoma bag change. Through their interviews, the majority of patients living with stoma expressed that they don’t get stoma bag of good quality, they don’t change regularly their stoma bag because of lack of means, and they don’t have enough knowledge on stoma care. They report complications such as itching and irritation of the surrounding area related to prolonged use of stoma bag. However a study done in Poland by Domonik et al showed that the majority of patients were satisfied with the quality of ostomy equipment with less complications.(41) Marquis et al found that the ability to change stoma bags and their appropriate bags demonstrated higher QoL scores.(42)

Our study participants expressed a change in their daily living conditions because of living with stoma, where they expressed emotions related to bad self-esteem, anxiety and self-discrimination in the society. They also express their feeling about being a burden to their families, lack of occupation, fear of being embarrassed in the public due to difficulties in changing stoma bags and even the unpleasant odor. They disclosed the fear of sexual relations, the lack of sexual desire and erectile dysfunction which is consistent with the findings from previous studies on psychological effects in patients living with stoma.(43)(40)(34)(35)(44)(23)(26)

Patients living with stoma often change or completely drop their occupation as result of psychosocial impact of living with stoma.(25)(45)(46)(34)(35) Previous studies found that most of stoma patients suffered negative psychological effects like depression , anxiety and limited social interaction(29)(31) Therefore, a special psychological follow up and management for patients with stomas is necessary. Pradeep et al suggested Education on diet modification by avoiding green leafy vegetables, use of bags with odor filters and deodorant products in the bags.(23)

## Study limitations

This study was limited to two tertiary hospitals in Rwanda and has a relatively small sample size. Therefore, the results may not be extrapolated to national level on quality of life of patients living with stoma.

As there is no validated translation form of stoma care quality of life questionnaire into the local language (Kinyarwanda) there might be imprecisions in the translated questionnaire used in the study.

Several factors are not considered in our study, such as: patients residency, comorbidities, neoadjuvant medications, and presence of metastasis in case of malignancy. Those factors could be addressed for future studies.

# CHAPTER VI: CONCLUSION AND RECOMMENDATION

## 6.1. Conclusion

The majority of patients living with stoma in tertiary hospital in Rwanda reported poor or worst health related quality of life. None of the study participants had a quality of life classified as “best”.

There is a strong relationship between quality of life of patients living with stoma and socio-economic status, age, duration of stoma, availability of stoma bag, type of stoma, education before and after surgery.

Availability of stoma bag, and education before and, after surgery have been identified as modifiable factors influencing QoL of patients living with stoma

Majority of participants feel that the lack of knowledge on how stoma care is done properly, lack of information from medical personnel, affordability and accessibility of stoma bags, lack of community based follow up and poor patient education on stoma and stoma-therapy may influence negatively their quality of life.

## 6.2. Recommendation

Based on the findings of this study, we recommend to establish a clear follow up plan of patients living with stoma.

We recommend training of stoma therapists/nurses at lower levels of health system so that follow up could be done much more regularly and nearby the patient’s homes and families.

Further, we recommend to train and include community Health workers in follow up of patients living with stoma in the community, scaling home-based care provision.

Targeted interventional programs on modifiable factors, such as: pre and post-surgery education of patients and their family, provision of Stoma bags on CBHI, and making stoma bags available in nearest health centers.

Creation of supporting groups within communities addressing psycho-social concerns of patients living with stoma.

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# ANNEXES

## ANNEX 1: Questionnaire

### QUESTIONNAIRE ON FACTORS INFLUENCING QUALITY OF LIFE OF PATIENTS LIVING WITH STOMA

Demographic Information

0.Initials ………. ID: ………………… Age: …….

Sex: Male ○ Female ○ District: ………………….

1. Type of stoma: Ileostomy ○ Colostomy ○

2. Elective surgery ○ emergency surgery ○

3. If colostomy, is it permanent ○ or temporary ○

4. What illness or diagnosis led to your need for an ostomy: benign ○ or malignancy ○

5. For how many months/years have you had your ileostomy or colostomy: …………………

6. What is your current weight (kg) ……………… weight (kg) before stoma: …………….

7. Ubudehe category: I II III IV

8. Type of insurance: ………………………………………………

9. Level of education: None ○ primary ○ secondary or VTC ○ university ○

10. Occupation: **Before stoma**

Farmer ○ Monthly paying job ○ Private paying job ○ No job ○

**After stoma**

Farmer ○ Monthly paying job ○ Private paying job ○ No job ○

11. What was your marital status prior to the surgery for your ostomy?

Single ○ Married ○ Divorced ○ Widowed ○ Separated ○

12. What is your marital status now?

Single ○ Married ○ Divorced ○ Widowed ○ Separated ○

13. Education before stoma creation: Yes ○ No ○

15. Education after stoma creation: Yes ○ No ○

16. Stoma bag : Available ○ Not available ○

17. Stoma quality of life scale

| **Item** | Always<br>(1) | Sometimes<br>(2) | Rarely<br>(3) | Never<br>(4) |
|---|---|---|---|---|
| **I become anxious when the pouch is full** | | | | |
| **I worry that the pouch will loosen** | | | | |
| **I feel the need to know where the nearest toilet is** | | | | |
| **I worry that the pouch may smell** | | | | |
| **I worry about noises from the stoma** | | | | |
| | | | | |
| **I need to rest during the day** | | | | |
| **My stoma pouch limits the choice of clothes that I can wear** | | | | |
| **I feel tired during the day** | | | | |
| **My stoma makes me feel sexually unattractive** | | | | |
| **I sleep badly during the night** | | | | |
| | | | | |
| **I worry that the pouch rustles** | | | | |
| **I feel embarrassed about my body because of my stoma** | | | | |
| **It would be difficult for me to stay away from home overnight** | | | | |
| **It is difficult to hide the fact that I wear a pouch** | | | | |
| **I worry that my condition is a burden to people close to me** | | | | |
| | | | | |
| **Avoid close physical contact with my** | | | | |

| | | | | |
|---|---|---|---|---|
| friends | | | | |
| My stoma makes it difficult for me to be with other people | | | | |
| I am afraid of meeting new people | | | | |
| I feel lonely even when I am with other people | | | | |
| I worry that my family feel awkward around me | | | | |

## ANNEX 2: Informed consent form

This consent form is for those who are invited to participate in our study on "**Factors affecting quality of life of patients living with stoma in tertiary hospital in Rwanda.** Meaning finding out how is the quality of life of patients living with stoma.

This form comprises of two sections:

**1. Introduction to the study.**
**2. Consent form.**

SECTION I: **Introduction to the study:**

We are going to explain and invite you to participate in this study. You will think about it and ask questions if necessary so that you understand the whole process, benefits and possible risks (although there are no expected risks) before you decide to accept to participate in this study.

My name is **Dr Niyonshuti Norbert**, a medical doctor by profession I'm also a senior resident in General surgery specialization program (master's degree) at University of Rwanda college of medicine and health sciences. We are carrying out a research on quality of life of patients living with stoma at Butare University Teaching Hospital, Kigali University Teaching Hospital so that we can evaluate modifiable factors to improve their quality of life.

**Objective of the study:**

The aim of this study is to release the knowledge on quality of life of patients living with stoma and awareness for possible modifiable factors that affect their quality of life.

**Methods of the study intervention:**

Our study will involve using a questionnaire, which will be given to participants to fill in their demographics and clinical data, social problems, and even economic issues. At the end will be put- together and analyzed to know the magnitude and characteristics of all patients, qualitative data will have recorded using questionnaire done after quantitative data and that will help us to make an appropriate conclusion.

**Participant selection:**

We invite all patients living with stoma and above 18 years old followed at CHUK, CHUB

**Right to participation:**

Your participation in this study is fully voluntary. You will continue to get same management as you have been receiving even if you choose not to participate. You are allowed to refuse to participate. This will not affect in anyway your deserved management.

**Duration of study:**

Survey questionnaire filling will take not more than 15 minutes. It will not delay your treatment schedules.

**Risks:**

This study is entirely safe there are no expected risks.

**Benefits and reimbursement:**

There is no reimbursement for any one's participation in this study.

**Confidentiality:**

The information that will be recorded from your charts or collected from you will be highly confidential. This information will be stored on a secured file in our password protected computer. Our questionnaire files have not included a NAME to protect the participant and only the researchers will have access to them.

**Sharing the results:**

We plan to publish the results for academic and research purposes and we shall feed back to the treatment team for self-evaluation, your confidentiality will always be protected throughout.

**CONTACTS:**

Door for questions is always open and in case you can contact the following:

Dr Niyonshuti Norbert: +250788902525, niyonshutinorbert@gmail.com.

CMHS IRB Chair Person: +250788490522.

CMHS IRB Deputy Chair Person: +250783340040.

SECTION II**: consent form.**

I have understood information provided all my questions have been answered to my satisfaction. I consent voluntarily to participate in this study.

**Printed name of participant: ……………………….**

**Signature/ thumb print of participant: …………………………….**

**Date: …………………………..**

**Statement by the researcher/individual obtaining consent:**

I have accurately read out the information sheet to the potential participant, and made sure that the participant understands the above information to my best of ability.

I confirm that the participant was given opportunity to ask questions about the study, and all the questions have been answered correctly to best of my knowledge.

I confirm that the individual has not been forced into giving consent; the consent has been given freely.

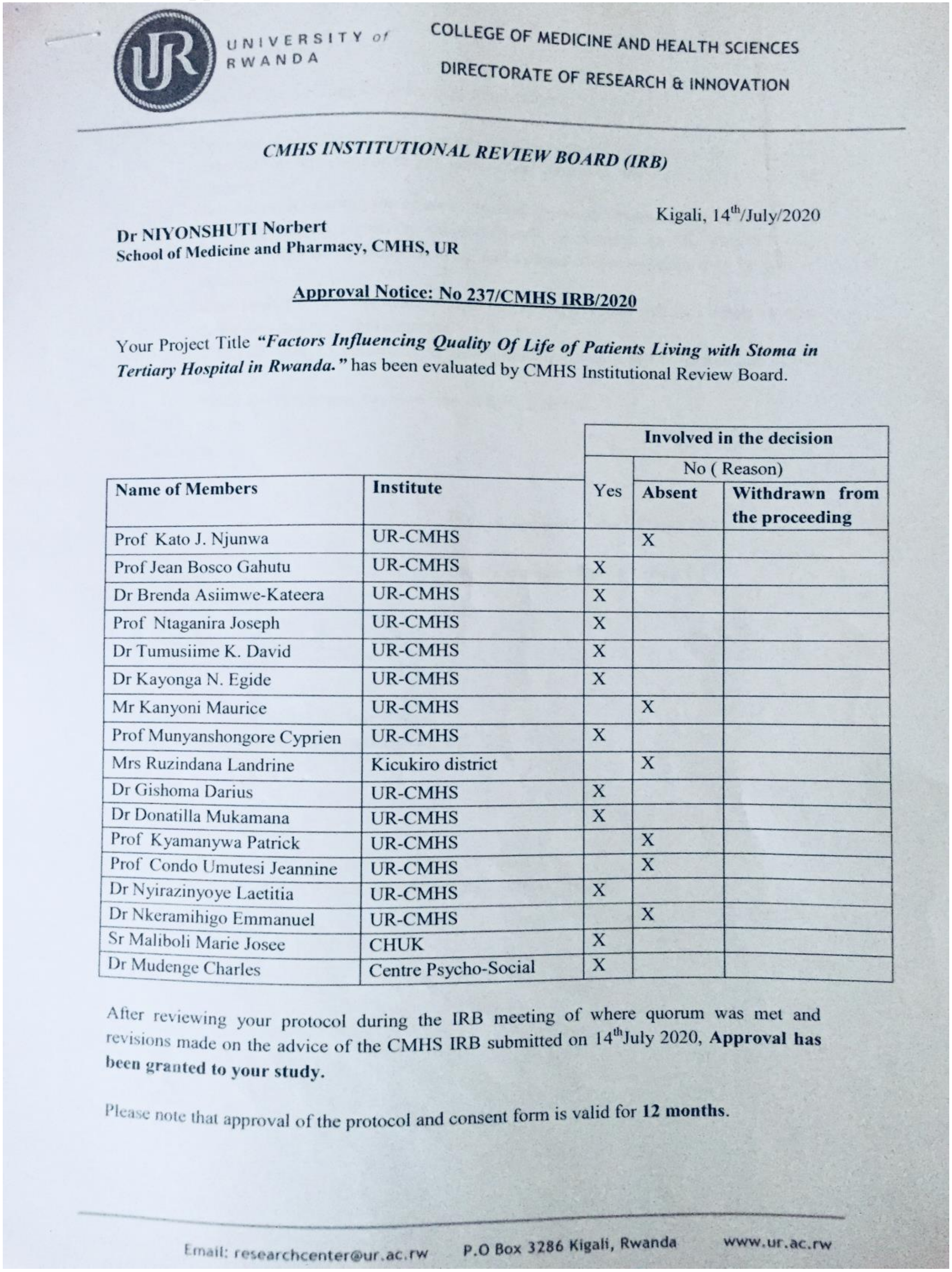
A copy of this consent form has been provided to the participant.

**Print name of Researcher/ person obtaining consent: ………………………….**

**Signature of Researcher/ person obtaining consent: ……………………………**

**Date: ………………………**

# ANNEX 3: IRB approval



UNIVERSITY of RWANDA

COLLEGE OF MEDICINE AND HEALTH SCIENCES
DIRECTORATE OF RESEARCH & INNOVATION

**CMHS INSTITUTIONAL REVIEW BOARD (IRB)**

Kigali, 14th/July/2020

**Dr NIYONSHUTI Norbert**
**School of Medicine and Pharmacy, CMHS, UR**

**Approval Notice: No 237/CMHS IRB/2020**

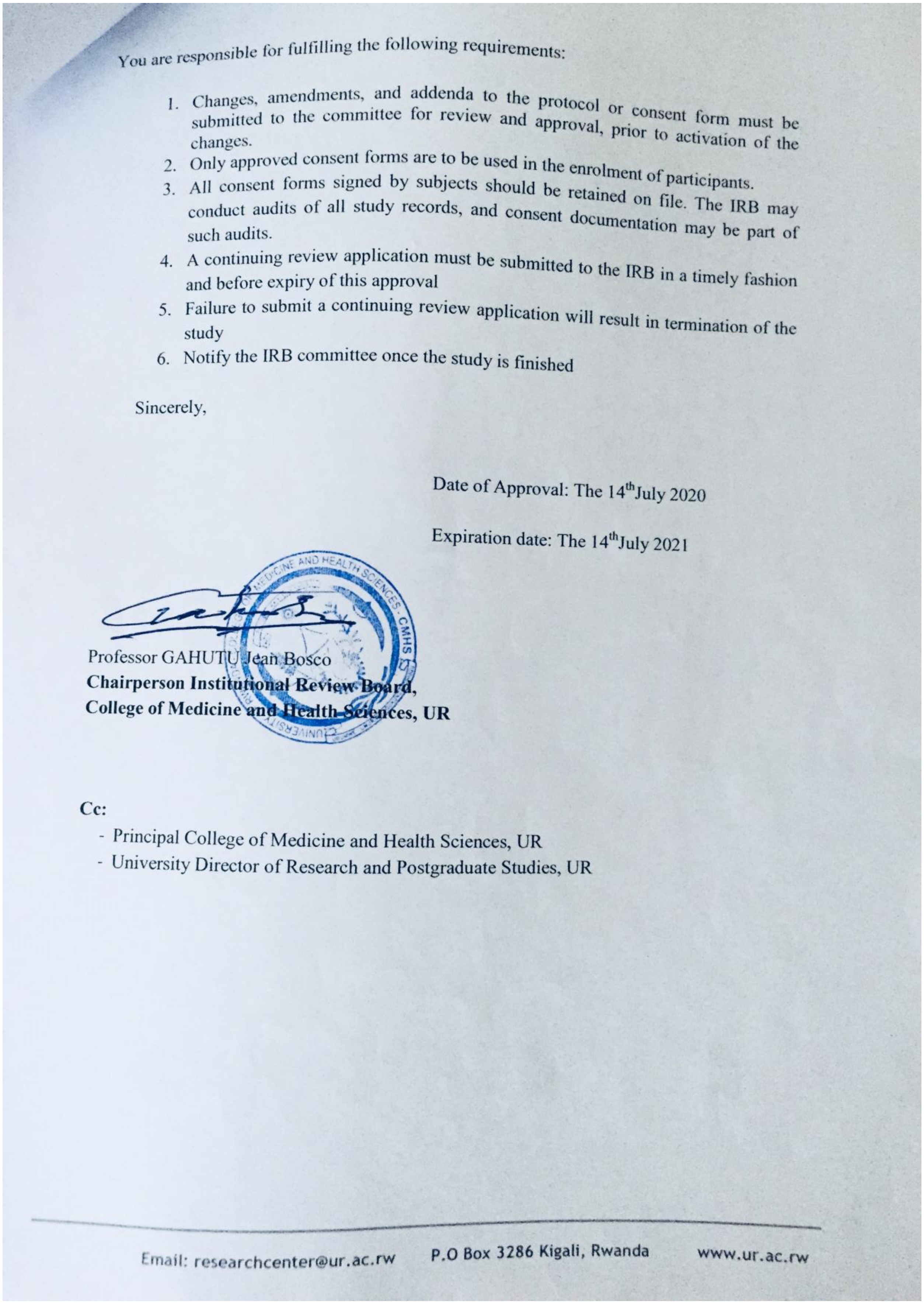
Your Project Title ***"Factors Influencing Quality Of Life of Patients Living with Stoma in Tertiary Hospital in Rwanda."*** has been evaluated by CMHS Institutional Review Board.

| | | **Involved in the decision** | | |
|---|---|---|---|---|
| | | | No ( Reason) | |
| **Name of Members** | **Institute** | Yes | **Absent** | **Withdrawn from the proceeding** |
| Prof Kato J. Njunwa | UR-CMHS | | X | |
| Prof Jean Bosco Gahutu | UR-CMHS | X | | |
| Dr Brenda Asiimwe-Kateera | UR-CMHS | X | | |
| Prof Ntaganira Joseph | UR-CMHS | X | | |
| Dr Tumusiime K. David | UR-CMHS | X | | |
| Dr Kayonga N. Egide | UR-CMHS | X | | |
| Mr Kanyoni Maurice | UR-CMHS | | X | |
| Prof Munyanshongore Cyprien | UR-CMHS | X | | |
| Mrs Ruzindana Landrine | Kicukiro district | | X | |
| Dr Gishoma Darius | UR-CMHS | X | | |
| Dr Donatilla Mukamana | UR-CMHS | X | | |
| Prof Kyamanywa Patrick | UR-CMHS | | X | |
| Prof Condo Umutesi Jeannine | UR-CMHS | | X | |
| Dr Nyirazinyoye Laetitia | UR-CMHS | X | | |
| Dr Nkeramihigo Emmanuel | UR-CMHS | | X | |
| Sr Maliboli Marie Josee | CHUK | X | | |
| Dr Mudenge Charles | Centre Psycho-Social | X | | |

After reviewing your protocol during the IRB meeting of where quorum was met and revisions made on the advice of the CMHS IRB submitted on 14thJuly 2020, **Approval has been granted to your study.**

Please note that approval of the protocol and consent form is valid for **12 months**.

Email: researchcenter@ur.ac.rw P.O Box 3286 Kigali, Rwanda www.ur.ac.rw



You are responsible for fulfilling the following requirements:

1. Changes, amendments, and addenda to the protocol or consent form must be submitted to the committee for review and approval, prior to activation of the changes.
2. Only approved consent forms are to be used in the enrolment of participants.
3. All consent forms signed by subjects should be retained on file. The IRB may conduct audits of all study records, and consent documentation may be part of such audits.
4. A continuing review application must be submitted to the IRB in a timely fashion and before expiry of this approval
5. Failure to submit a continuing review application will result in termination of the study
6. Notify the IRB committee once the study is finished

Sincerely,

Date of Approval: The 14thJuly 2020

Expiration date: The 14thJuly 2021

Professor GAHUTU Jean Bosco
**Chairperson Institutional Review Board,**
**College of Medicine and Health Sciences, UR**

**Cc:**

- Principal College of Medicine and Health Sciences, UR
- University Director of Research and Postgraduate Studies, UR