Capstone Practicum Report

Assessing The Prevalence of Intestinal Stomas Among Major Abdominal Surgery Patients and Exploring the Lived Experience of Long-Term Ostomates in Rwanda: A Mixed Methods Study

By

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DECLARATION

I, Mutesi Mukinisha, hereby declare that the practicum capstone thesis has been written by me without any external unauthorized help, that it has been neither presented to any institution for evaluation nor previously published in its entirety or in parts. Any parts, words or ideas, of the thesis, however limited, which are quoted from or based on other sources, have been acknowledged as such without exception.

Signature: MM Date: November 21, 2025

DEDICATION

To my Jaja, Rose Nyirabagoyi, for believing in me and for your constant encouragement; "*rasanira gutsinda"* has been both a blessing and a push when I needed it most.

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ABSTRACT

Introduction

Intestinal stoma formation is a critical but often under documented surgical intervention in Rwanda, typically performed to manage bowel obstruction, be it benign or malignant, perforation, or trauma. Despite its clinical significance, little is known about the national prevalence of stoma formation or the lived experiences of individuals adapting to long-term stoma use.

Objectives

This study aimed to (1) estimate the prevalence of intestinal stomas among abdominal surgery patients in Rwanda in 2024, (2) describe the demographic and clinical characteristics among abdominal surgery patients in Rwanda in 2024, (3) assess the association between selected demographic and clinical characteristics and the likelihood of stoma formation among abdominal surgery patients in Rwanda in 2024, and 4) explore the medical, social, psychological, and economic challenges experienced by individuals with long-term stomas.

Methods

A mixed-methods design was employed. Quantitative data were retrospectively extracted from 509 abdominal surgical theater registries across referral and level two teaching hospitals (L2TH) and analyzed using chi-square and Fisher's exact tests, where appropriate in SPSS. Qualitative data were collected through semi-structured interviews with 11 individuals living with long-term stomas and analyzed thematically using Dedoose.

Results

Of the 509 patients that underwent major abdominal surgery, the prevalence of stoma formation was 12%. Stomas were significantly associated with age, hospital type, and etiology (all $p<0.05$). No significant association was found with sex ($p=0.834$). Qualitative findings indicated that living with a stoma involved persistent physical, emotional, and social challenges, compounded by supply shortages, financial barriers, and limited institutional support. Participants also described acceptance, spirituality, and social support as key coping mechanisms that fostered adaptation.

Conclusion

Stoma formation in Rwanda was more prevalent among older adults and patients with malignancy, with notable differences across hospital types. Beyond clinical determinants, the lived experience of individuals with stomas was shaped by ongoing material, psychosocial and structural constraints. Strengthening stoma care supply chains, improving patient support systems, and integrating psychosocial care are essential to enhance long-term wellbeing and quality of life for ostomates

Keywords

Intestinal stoma, colorectal cancer, lived experience, Rwanda, stoma care, mixed methods

LIST OF TABLES

LIST OF ABBREVIATIONS

CBHI	Community-Based Health Insurance
CHUB	Centre Hospitalier Universitaire de Butare
CHUK	Centre Hospitalier Universitaire de Kigali
HIC	High-Income Country
LMIC	Low- and Middle-Income Country
MoH	Ministry of Health
NSOAP	National Surgical, Obstetric, and Anesthesia Plan
RMH	Rwanda Military Hospital
L2TH	Level Two Teaching Hospital
SD	Standard Deviation
SPSS	Statistical Package for the Social Sciences
UGHE	University of Global Health Equity
WHO	World Health Organization

TABLE OF CONTENTS

CHAPTER 1: INTRODUCTION

Intestinal stoma formation is a critical surgical intervention used to manage different abdominal pathologies including severe gastrointestinal trauma, infection, obstruction, malignancy, or congenital abnormality, especially when direct bowel continuity cannot be maintained (Hendren et al., 2015). While it is a life-saving procedure, having a stoma can significantly affect long-term quality of life, with complex implications across physical, psychological, social, and economic domains (Farahani et al., 2022; Vural et al., 2016)

In high-income countries (HICs), stomas are more commonly created during planned oncological surgeries, whereas in low- and middle-income countries (LMICs), they are often created in emergency settings due to late hospital presentation, delayed diagnosis, and limited surgical capacity (Massenga et al., 2019). For the purposes of this study, a long-term stoma is defined as an intestinal stoma maintained for six months or longer.

Although Rwanda lacks published national data, internal hospital audits and master's thesis reviews suggest a rising number of stoma cases, many of whom require emergency procedures or present with infection-related conditions. (Niyonshuti, 2021; Umugwaneza, 2021). Peer-reviewed East African studies report similar patterns with increases in stoma formation driven by delayed presentation and infection-related complications (Engida et al., 2016; Massenga et al., 2019). An intestinal stoma is a surgically created opening on the abdominal wall that brings a segment of bowel to the skin surface to divert fecal flow (Hendren et al., 2015). For the purposes of this study, a long-term stoma is defined as one maintained for six months or longer, consistent with follow-up standards in surgical literature (Albulescu et al., 2023). Rwanda has also experienced a rising incidence of colorectal cancer in recent years, with global cancer surveillance data indicating an upward trend nationally (WHO, 2024). Because late-stage colorectal cancer frequently requires bowel diversion, this epidemiological shift further underscores the need for updated context-specific evidence on stoma prevalence and patient outcomes.

This lack of context-specific evidence limits Rwanda's ability to develop and scale adequate postoperative psychosocial and rehabilitation care for individuals with stomas. This study therefore seeks to address that gap by quantifying the prevalence of intestinal stomas and exploring the multidimensional challenges experienced by individuals living with long-term stomas in Rwanda.

1.1 Problem Statement

National data on the prevalence of intestinal stomas in Rwanda are currently unavailable, and little is known about the lived experiences of long-term stoma users. This lack of evidence limits effective planning for stoma care, supply procurement, and patient support services. Without reliable prevalence estimates and experiential data, health system responses to stoma care remain fragmented and reactive rather than evidence-informed. Estimating the burden of intestinal stomas and understanding the experiences of individuals with long-term stomas would inform the design of programs to improve healthcare delivery and resource allocation.

1.2 Objectives of the Study

The following study objectives would be accomplished by November 2025 in Rwanda:

1. To estimate the prevalence of intestinal stomas among abdominal surgery patients in Rwanda in 2024
2. To describe the demographic and clinical characteristics among abdominal surgery patients in Rwanda in 2024,
3. To assess the association between selected demographic and clinical characteristics and the likelihood of stoma formation among abdominal surgery patients in Rwanda in 2024
4. To explore the medical, social, psychological, and economic challenges experienced by individuals with long-term stomas.

1.3 Hypothesis

It was hypothesized that selected demographic and clinical characteristics are associated with the likelihood of intestinal stoma formation among abdominal surgery patients in Rwanda.

1.4 Organization of the Report

This report is organized into six chapters that follow a logical structure to present the study in a clear and comprehensive manner. It begins with an abstract summarizing the study's context, methods, key findings, and implications.

The first chapter provides an introduction to the study, outlining the background and context of intestinal stoma formation, presenting the problem statement, and stating the research objectives.

The second chapter presents an in-depth literature review, starting with global perspectives on stoma prevalence, clinical challenges, and patient experiences, and narrowing down to the specific context in Rwanda. It is followed by laying out gaps and proposing a justification for conducting the study.

The third chapter explains the methods used for both the quantitative and qualitative components of the study, including study design, setting, sampling methods, data collection tools, procedures, and the steps followed for data management and analysis. Chapter four presents the combined results from the quantitative and qualitative strands, including statistical findings and thematic interpretations.

The fifth chapter offers a discussion of the findings, comparing them with existing literature, highlighting new insights, addressing potential challenges and limitations, and reflecting on the implications for healthcare delivery and policy in Rwanda. Finally, the sixth chapter concludes the report with a summary of key findings and offers recommendations for policy, practice, and future research.

CHAPTER TWO: LITERATURE REVIEW

2.1 Definition, Prevalence and Indications for Stoma Formation

Intestinal stomas, or ostomies, are surgical openings created to divert waste from the gastrointestinal tract, typically brought to the abdominal surface for excretion (Hendren et al., 2015). They are generally classified as ileostomies or colostomies, depending on whether the diversion is from the small or large intestine, respectively. Globally, precise population-level estimates of stoma prevalence remain limited, as most data are derived from hospital-based surgical series rather than national registries. However, studies show that stoma creation is primarily associated with colorectal cancer, inflammatory bowel disease, diverticulitis, and traumatic or obstructive bowel conditions (Albulescu et al., 2023; Hendren et al., 2015). The absence of standardized global surveillance systems for stoma formation contributes to substantial variation in reported prevalence across regions. In high-income countries (HICs), most stomas are created electively and are often temporary, placed during planned oncological or

inflammatory bowel disease surgeries (Ng et al., 2020). In contrast, in low- and middle-income countries (LMICs), stoma formation is more commonly the result of emergency laparotomy due to late presentation, bowel perforation, intestinal obstruction, or traumatic injury (Massenga et al., 2019). This divergence reflects broader inequities in access to early diagnosis, screening, and specialist surgical care. In sub-Saharan Africa, evidence on stoma prevalence is sparse and fragmented. A study from Tanzanian reported that 8.1% of all emergency abdominal surgeries resulted in stoma formation, most commonly due to peritonitis, sigmoid volvulus, and typhoid perforation (Massenga et al., 2019).

In Rwanda, evidence remains limited and fragmented. While several dissertation and hospital-based reviews document postoperative complications, surgical burden, and abdominal emergency patterns, none have established national-level estimates of stoma (Niyonshuti, 2021; Umugwaneza, 2021). Local research suggests that stomas are often created under emergency conditions and that long-term stoma users face persistent medical and psychosocial challenges, but data remains confined to small samples and single facilities (Mpirimbanyi et al., 2020). Regional evidence strengthens this context, with peer-reviewed studies from Tanzania and Ethiopia showing similar patterns of emergency stoma creation driven by obstruction, perforation, and infection (Engida et al., 2016; Massenga et al., 2019). Research from Uganda likewise demonstrates that delayed presentation and peritonitis remain key drivers of stoma formation in East Africa (Ssewanyana et al., 2021).

In a broader epidemiological context, global surveillance reports rising colorectal cancer incidence, including in sub-Saharan Africa, which may influence future stoma trends (WHO, 2024)

Although colorectal cancer, inflammatory bowel disease (IBD), and diverticular disease are among the leading indications for stoma formation in high-income countries, studies consistently report low rates of these conditions in sub-Saharan Africa. However, researchers debate whether these low figures represent a true epidemiologic difference or are the result of diagnostic barriers, limited access to colonoscopy, and misclassification of gastrointestinal disease (Hodges & Kelly, 2020; Ng et al., 2020). Some studies suggested that as diets westernize and urbanization increases, cases of IBD and diverticulitis may rise in African countries, but current data remain

insufficient and inconsistent (Alnzaer et al., 2020; Vally et al., 2017). This uncertainty further reinforces the need for context-specific research.

2.2 Complications and Physical Challenges

The physical effects of stoma formation extend beyond the initial surgery, with long-term complications including skin excoriation, leakage, prolapse, obstruction, and parastomal hernia (Albulescu et al., 2023). Rates of complications are higher in resource-limited settings where specialized ostomy care is unavailable, and patients rely on inconsistent follow-up (Umesh et al., 2016). Complications of ostomy significantly affect the quality of life of ostomates. There is little evidence on the rate of long-term complications in ostomates, especially from the developing countries which include Sri Lanka. This study was aimed at describing the long-term complications of enteral ostomies and their contributory factors. A study of long-term complications associated with enteral ostomy and their contributory factors. (Umesh et al., 2016). Studies from Rwanda and Ethiopia report that many patients experience difficulties in changing bags, cleaning the peristomal area, and preventing infection due to limited supplies and lack of trained stoma nurses (Aboma & Kaba, 2023; Niyonshuti, 2021).

In several LMIC settings, patients report reusing bags or improvising with plastic, cloth, or locally made adhesive materials, increasing risk for infection, skin breakdown, and reduced dignity (Chery et al., 2024; Valadares de Oliveira et al., 2018). These challenges have direct implications for hygiene and daily functioning, especially for patients living in rural areas with limited water access.

2.3 Psychosocial and Emotional Impact

Individuals with stomas report significant changes in identity, self-image, and emotional well-being. Feelings of shame, loss of confidence, anxiety, and depression are widely documented, particularly where stigma surrounding altered bodily function is present (Capilla-Díaz et al., 2019; Farahani et al., 2022). In LMICs, the inability to hide a

stoma can contribute to social withdrawal due to fear of odor, leakage, or public embarrassment (Ssewanyana et al., 2021).

Sexual intimacy is a frequently reported area of disruption, especially among adults of reproductive age who associate the stoma with loss of attractiveness or fear of partner rejection (Ayik et al., 2019; Vural et al., 2016). Studies show that stoma users often avoid relationships or report reduced sexual satisfaction due to discomfort, pain, or fear of accidental leakage during intimacy. These experiences are intensified where counseling, support groups, and rehabilitative services are lacking.

2.4 Financial Burden and Access to Supplies

Consistent access to stoma care materials is one of the most defining predictors of quality of life for ostomates in LMICs. In many African countries, ostomy bags are not fully covered by national insurance, leaving patients to pay out of pocket for recurring supplies (Ssewanyana et al., 2021). For ostomates who must change bags daily, associated costs create long-term financial strain for households already experiencing economic hardship. As a result, many patients ration their supplies, wear bags longer than recommended, or use alternatives such as plastic bags or cloth, which increases infection risk and decreases comfort (Chery et al., 2024). Limited availability at L2THs further drives patients to depend on private pharmacies, charity donations, or family support to secure supplies (Valadares de Oliveira et al., 2018).

2.5 Health System and Policy Limitations

In many high-income countries, structured stoma care pathways exist, including preoperative counseling, postoperative home visits, and trained stoma care nurses (Hendren et al., 2015). These systems significantly improve postoperative outcomes and reduce complications. However, most LMICs, including Rwanda, lack specialized services, formal stoma care guidelines, and medical staff trained in ostomy management (Niyonshuti, 2021).

Care is typically delivered by surgeons and general nurses who have limited time for long-term patient follow-up. No national registry exists to track stoma patients or their long-term outcomes, making service planning difficult and reactive rather than preventive.

2.6 Existing Interventions

Existing global interventions show that structured stoma care systems can significantly improve patient outcomes. Studies from Europe, Brazil, and Ethiopia demonstrate that trained stoma nurses, early postoperative teaching, dedicated ostomy clinics, and peer-support groups reduce complications, increase self-efficacy, and improve quality of life (Valadares de Oliveira et al., 2018). Such programs emphasize early counselling, routine follow-up, and psychosocial support, yet remain sparse across most African health systems. Several East African countries offer relevant examples. In Ethiopia, decentralized ostomy follow-up clinics staffed by trained nurses have reduced unplanned readmissions and improved self-care (Engida et al., 2016). At Mulago National Referral Hospital in Uganda, nurse-led stoma education and structured follow-up pathways have enhanced postoperative recovery and patient confidence (Ssewanyana et al., 2021). Rwanda currently lacks comparable stoma-care pathways or specialized ostomy nursing services, highlighting the need to adapt feasible regional approaches and integrate evidence-based models into national surgical care.

2.7 Gap in Existing Evidence

Although African and global studies underscore the physical, psychosocial, and financial burdens associated with stoma formation, there remains no national-level estimate of stoma prevalence in Rwanda and no published research documenting the lived experiences of long-term stoma users in the country. Previous work-including single-site studies, case reviews, and master's dissertations-provides useful foundations, though detailed qualitative accounts of lived experience remain scarce (Niyonshuti, 2021; Umugwaneza, 2021).

This gap limits the ability of health institutions and the Ministry of Health to plan stoma care services, allocate supplies, or design psychosocial rehabilitation programs.

2.8 Justification for the Study

This study responds directly to the unmet evidence needs in Rwanda by (1) establishing the first empirical estimate of stoma prevalence using multicenter, retrospective surgical data, and (2) documenting the social, physical, emotional, and economic realities of individuals living with long-term stomas. The findings will provide evidence that may support resource planning, procurement decisions, training needs assessment, and policy development for equitable and sustainable stoma care in Rwanda. It also contributes to the broader global effort to correct the evidence imbalance between HIC and LMIC research and to ensure that clinical and public health decisions are informed by locally generated data rather than extrapolated assumptions.

CHAPTER THREE: METHODS

Study Design

This study employed a mixed methods design, combining a retrospective quantitative component and a qualitative descriptive component. The quantitative phase aimed to determine the prevalence as well as demographic and clinical characteristics of intestinal stomas using patient data from theatre registers from 2024. The qualitative phase explored the lived experiences of individuals with long-term stomas through in-depth semi-structured interviews. This design enabled the use of both numbers and personal stories to see not only how many people are affected, but also the impact it has on their daily lives, offering a fuller understanding of stoma care in Rwanda.

3.1 Quantitative Study

3.1.1 Study Setting

The quantitative component was conducted across nine hospitals in Rwanda, including:

- Four referral hospitals: Kigali University Teaching Hospital (CHUK), Butare University Teaching Hospital (CHUB), Rwanda Military Hospital (RMH), and King Faisal Hospital (KFH).
- Five Level Two Teaching Hospitals (L2TH), representing different provinces: Rwamagana (East), Kibogora (West), Ruhengeri and Butaro (North), and Kabgayi (South).

These facilities collectively offer a representative range of urban and rural surgical contexts, as they include all national referral hospitals and at least one L2TH per province.

3.1.2 Sampling and Participants

The sample size was estimated using the Kish and Leslie formula:

$n = Z^2pq/d^2$

Where:

n = Sample size

Z = Z-score for the desired confidence interval, set at 1.96 for 95% confidence

p = Assumed true population prevalence of people with intestinal stomas, set at 50% (0.5) as there is no available data on population prevalence with who received an intestinal stoma during surgery

q = complement of p; (1-p), 50% (0.5)

D = margin of error, set at 0.05

With confidence level set at 95%, an estimated prevalence of 50%, and 5% margin of error, the calculated sample size was 385. Referral and L2THs in Rwanda perform thousands of non-obstetric operations annually (MOH, 2018), indicating that a one-year retrospective period would provide sufficient eligible cases even with some incomplete records. Surgical registers from January1, 2024 to December 31, 2024 were therefore reviewed.

Included criteria

All theater records of adult patients (≥18 years) who underwent major abdominal surgery (benign bowel obstruction, perforation, anastomotic leak, trauma, malignancy, ischemia, and intra-abdominal infection/inflammation).

3.1.3 Data Collection Tools

An Excel-based abstraction tool (Appendix 2) was used to systematically collect data on demographic characteristics (including age, sex, region of residence), clinical factors (such as type of hospital and surgical indication), and procedural details (including surgery type and stoma outcome). Prior to full deployment across all study sites, the tool was piloted at Ruhengeri L2TH, where it was tested on 112 patient records to ensure clarity and consistency in data collection. This process did not result in any refinement as the tool demonstrated adequate clarity and internal consistency and was therefore deployed in its original form across all study sites. The data collected from the pilot phase was left in the sample that was analyzed.

3.1.4 Data Collection Procedures

Prior to data collection, ethical approval was obtained from the University of Global Health Equity Institutional Review Board (UGHE-IRB), Ref: UGHE-IRB/2025/363, approval date August 7, 2025. Subsequently, research

authorization from the Rwanda Ministry of Health (MOH), Nº 20/1064/DPMEHF/2025, as well as written permission were secured from each participating hospital, following the ethical considerations (Appendix 4).

Theatre registers were reviewed to extract data on all eligible abdominal surgeries performed between January 1 and December 31, 2024. Two data collectors who received training on the data abstraction tool and the terminology during the pilot phase, independently abstracted information from the registers using consecutive sampling of all eligible cases, with datasets subsequently cross-checked for accuracy and consistency. Final verification was conducted by the principal investigator to ensure completeness and reliability of the collected data.

3.1.5 Data Collectors

Data was abstracted by the principal investigator and two data collectors. Data collectors were oriented on the data abstraction tool and key variable definitions to ensure consistency. Reliability checks and quality control reviews were conducted to ensure accuracy and consistency across data collectors. These included cross-checking extracted data against surgical theatre registers and resolving discrepancies through joint review prior to final data entry.

3.1.6 Key Measures

- Stoma prevalence: the percentage of patients with stoma after major abdominal surgeries (benign bowel obstruction, perforation, anastomotic leak, trauma, malignancy, ischemia, and intra-abdominal infection/inflammation).
- Stoma type: the percentage of patients with Ileostomy, colostomy, or both
- Other patient variables included age, sex, preoperative diagnosis, hospital type.

3.1.7 Data Management

All data abstracted from theatre registers was entered into a customized Excel spreadsheet by the principal investigator and the two data collectors. All records were de-identified and assigned a numeric code to protect

patient confidentiality. The dataset was stored in a password-protected folder accessible only to the principal investigator and authorized research advisors.

Following data entry, a systematic data cleaning process was undertaken to ensure completeness and to remove inconsistencies. The cleaned dataset was then exported to SPSS for statistical analysis. All electronic data files were stored on a secure, password-protected device with no identifying information retained in the final dataset. The data will be kept at UGHE for 10 years according to IRB requirements.

3.1.8 Data Analysis

Descriptive statistics were used to summarize demographic characteristics, clinical variables, and key measures. The association between stoma formation (dependent variable) and selected demographic and clinical variables was examined using chi-square and Fisher's exact tests, where appropriate. All statistical analyses were performed using SPSS with statistical significance set at a p-value of <0.05.

3.2 Qualitative Study

3.2.1 Study Setting

The qualitative component was conducted at Butaro L2TH, located in Northern Rwanda. Although interviews were conducted from a single site, participants not only resided in different regions, but they had also had their stoma surgeries from multiple hospitals across the country (including CHUK, CHUB, RMH, and Kibogora), ensuring diversity of experiences.

3.2.2 Sampling and Participants

A purposive sampling of participants who had sought stoma care or follow-up in the past two years was undertaken, and the final sample size of 11 participants was determined by thematic saturation consistent with emerging qualitative evidence showing that for homogenous populations saturation is often achieved within 9–17 interviews (Hennink & Kaiser, 2022).

Inclusion Criteria

- Living with a stoma for 6 months or longer
- Aged 18 or older
- Fluent in English or Kinyarwanda

Exclusion Criteria

- Critically ill
- Unable to participate due to communication impairments without a proxy

3.2.3 Data Collection Tools

The semi-structured interview guide (Appendix 3) was adapted from previous qualitative studies exploring the lived experiences of individuals with stomas in low-resource settings (Aboma & Kaba, 2023; Chery et al., 2024). Its structure was informed by recurring thematic domains identified in the literature, including emotional, physical, social, and financial impacts of long-term stoma use. The guide consists of open-ended questions designed to elicit participants' narratives in their own words, from the moment of diagnosis through their period of adjustment. Probing questions were used to explore specific domains in greater depth, such as daily physical challenges related to stoma care, emotional responses like fear, isolation, or acceptance, changes in personal relationships and community participation, financial implications of procuring stoma supplies, and experiences with health system support. This approach ensured flexibility to follow participant priorities while maintaining consistent coverage of core study topics. Prior to data collection, the interview tool was pretested on two individuals to ensure clarity, appropriateness of wording, and flow of questions. Feedback from this pretest was used to make minor adjustments for improved usability.

3.2.4 Data Collection Procedures

Eligible participants were identified through Butaro L2TH's patient follow-up database and initially contacted individually by phone or in person. During this first contact, the study's purpose and scope were explained,

including the voluntary nature of participation, estimated interview duration, and assurances of confidentiality. Participants were given time to ask questions and consider their involvement before agreeing to participate.

Those who agreed were invited to schedule an interview at the time and location of their choice, either face-to-face or by phone, to accommodate distance, mobility limitations, and personal preference. Before each interview began, the study procedures and ethical safeguards were reiterated, and participants were reminded of their right to decline any question or withdraw from the study at any time without consequence to their care.

Written informed consent was obtained for in-person interviews, while verbal consent was accepted and recorded for phone-based sessions. With the participant's approval, interviews were audio-recorded; if consent for recording was withheld, detailed field notes were taken instead. All interviews were conducted by the principal investigator in Kinyarwanda to ensure cultural and linguistic familiarity and each lasted approximately 30 minutes.

3.2.5 Data Collectors

All interviews were conducted solely by the principal investigator, who is fluent in both Kinyarwanda and English, allowing for effective communication and participant comfort during the data collection process.

3.2.6 Qualitative Domains of Inquiry

- Initial reaction to stoma surgery
- Physical challenges
- Psychosocial impact
- Economic effects
- Coping strategies and sources of support

3.2.7 Data Management

Audio files were deleted from the recording device immediately after being transferred to a password-protected laptop to minimize security risks. All recordings were transcribed verbatim in Kinyarwanda by trained data collectors and subsequently translated into English. To ensure accuracy, each translation was cross-checked daily by a bilingual team member familiar with both the language and the study context.

Transcripts were fully anonymized by removing names, specific locations, and any other identifiable information. All digital files, including transcripts and digitized field notes, were stored on a password-protected computer accessible only to the principal investigator.

In accordance with institutional data management policy, all research data will be securely retained for ten years after the completion of the study.

3.2.8 Data Analysis

Thematic analysis was used to interpret and organize the qualitative data. All interview transcripts were read and coded by the principal investigator using an inductive approach to allow themes to emerge directly from participants' narratives. An initial codebook was developed during the early stages of analysis and refined iteratively through memos, reflection, and repeated engagement with the data. Codes were then organized into broader conceptual categories, which informed the development of the final themes.

To enhance credibility and reduce researcher bias, the principal investigator held periodic debriefing sessions with external qualitative researchers and study advisors to review coding decisions and discuss emerging interpretations. Verbatim excerpts as well as field notes from participant interviews were retained throughout the analysis to support analytical transparency and ensure that themes faithfully represented participant perspectives. All qualitative data management and analysis were conducted using Dedoose software.

CHAPTER FOUR: RESULTS

The four research objectives were: (1) to determine the prevalence of intestinal stomas among abdominal surgery patients in Rwanda in 2024; (2) to describe the demographic and clinical characteristics of patients who received stomas; (3) to assess the association between demographic and clinical characteristics and the likelihood of stoma formation; and (4) to explore the medical, psychological, social, and economic challenges experienced by individuals living with a stoma for at least six months.

4.1 Quantitative Study Results

4.1.1 Characteristics of the Quantitative Study Sample

A total of 509 surgical patients who underwent major abdominal surgery as defined in the methods were identified across all study sites between January 1, 2024 and December 31, 2024. The mean age of participants was 45.7 years (SD = 18.3), with 169 (33%) aged 18-35 years, 192 (38%) between 36–59 years, 135 (27%) 60 years or older, and 13 (3%) did not indicate age.

Out of all participants, 346 participants (68%) were male, 160 (31.4%) were female, 90 (17.7%) participants were from the Northern Province, 23 (4.5%) from the Southern Province, 3 (0.6%) from the Eastern Province, 86 (16.9%) from the Western Province, 14 (2.8%) from Kigali City. 293 (57.6%) did not have reported information on their residence.

Regarding insurance, 226 participants (44.4%) were registered under Mutuelle de Santé/Community Based Health Insurance (MUSA/CBHI), 38 (7.5%) under other insurance types, including Prime, RAMA/RSSB, UAP, BRITAM, SANLAM, as well as out of pocket, and 245 (48.1%) had missing insurance information. Among all procedures, 385 (75.6%) were performed in referral hospitals and 124 (24.4%) in L2THs. The identified surgical indications were benign obstruction (n = 222, 43.6%), infection or inflammation (n = 150, 29.5%), perforation or leak (n = 55, 10.8%), malignancy (n = 45, 8.8%), and trauma (n = 37, 7.3%) (Table 1).

Table 1: Socio-demographic and clinical characteristics of patients who underwent abdominal surgery in selected hospitals in Rwanda (January 1 - December 31, 2024)

Variable	Category	N (%)
Sample		509
Mean Age (SD)		45.7 (18.3)
Age group	18-35	169 (33)
	36-59	192 (38)
	60+	135 (27)
	Missing	13 (3)
Sex	Female	160 (31.4)
	Male	346 (68.0)
	Missing	3 (0.6)
Residence	North	90 (17.7)
	South	23 (4.5)
	East	3 (0.6)
	West	86 (16.9)
	Kigali	14 (2.8)
	Missing	293 (57.6)
Insurance	MUSA/CBHI	226 (44.4)
	Others	38 (7.5)
	Missing	245 (48.1)
Hospital type	Referral	385 (75.6)
	L2TH	124 (24.4)
Etiology	Benign obstruction	222 (43.6)
	Infection	150 (29.5)
	Malignancy	45 (8.8)
	Perforation/leak	55 (10.8)
	Trauma	37 (7.3)

SD – Standard Deviation, MUSA/CBHI – *Mutuelle de Sante*/ Community Based Health Insurance, L2TH – Level Two Teaching Hospital

4.1.2 Prevalence and Distribution of Stoma Formation

Among the 509 patients, 61 (12%) underwent stoma formation. Of the patients with a stoma, 44 (72.1%) received a colostomy, 12 (19.6%) received an ileostomy, and 5 (8.1%) had both types of stoma (Table 2).

Table 2: Prevalence and distribution of Stoma formation among patients who underwent abdominal surgery in selected hospitals in Rwanda (January 1 - December 31, 2024)

		N (%)
Stoma formation	Yes	61 (12)
	No	448 (88)
Stoma type (N=61)	Colostomy	44 (72.1)
	Ileostomy	12 (19.6)
	Both	5 (8.1)

4.1.3 Associations between characteristics and stoma formation

Three factors were found to have a significant association with stoma formation. 1) Age group (p = 0.007). Of the 61 patients that received a stoma, participants aged 18–35 years accounted for 13 (7.7%) of stoma cases, those aged 36–59 years for 22 (11.5%), and those aged 60 years and older for 26 (19.3%). 2) Hospital type (p < 0.001), with 34 (8.8%) from referral hospitals and 27 (21.8%) from L2THs. 3) Etiology (p < .001), with 27 (12.2%) benign obstruction, 9 (6.0%) infection, 19 (42.2%) malignancy, and 6 (10.9%) perforation or leak.

Sex was not significantly associated with stoma formation (p = .834). Residence and insurance data were not analyzed due to high proportions of missing data (57.6% and 48.1%, respectively), and comparative checks showed that their absence did not meaningfully alter the overall distribution of the key measures (Table 3).

Table 3: Association between socio-demographic and clinical characteristics and stoma formation among abdominal surgery patients in Rwanda (January 1 - December 31, 2024)

Variable	Category	Stoma (%)	No Stoma (%)	P value
Age group	18-35	13 (7.7)	156 (92.3)	0.007*
	36-59	22 (11.5)	176 (91.7)	
	60+	26 (19.3)	109 (80.7)	
Sex	Female	20 (12.5)	140 (87.5)	0.834
	Male	41 (11.8)	305 (88.2)	
Hospital type	Referral	34 (8.8)	351 (91.2)	<0.001*
	L2TH	27 (21.8)	97 (78.2)	
Etiology	Benign obstruction	27 (12.2)	195 (87.8)	<0.001*
	Infection	9 (6.0)	141 (94.0)	
	Malignancy	19 (42.2)	26 (57.8)	
	Perforation/leak	6 (10.9)	49 (89.1)	
	Trauma	0 (0.0)	37 (100)	

*Significant at P<0.05, L2TH – Level Two Teaching Hospital

4.2 Qualitative Study Results

Lived experiences of individuals with stoma

A total of 11 participants who had been living with a stoma for at least six months participated in semi-structured in-depth interviews. The group included six males and five females, ranging in age from 30 to 72 years, with a median age of 60 years (Table 4).

Table 4: Summary of interviewed participants who had been ostomates for more than 6 months

ID	Sex	Age (Years)	Length of stoma (Years)
01	F	72	4
02	M	65	1
03	M	34	2
04	F	65	4
05	M	68	2
06	F	58	3
07	F	45	2
08	F	30	4
09	M	60	5
10	M	47	2
11	M	65	2

Three major themes emerged in describing the lived experiences of patients managing long-term stomas in Rwanda:

Theme 1: Living with a stoma imposed ongoing physical, emotional, and social challenges to daily life

Participants explained that life after stoma surgery involved extensive adjustment across nearly every area of everyday functioning. What had once been routine or effortless now required planning to manage the discomfort or the visibility of the stoma. The impact was not just physical but emotional and relational, altering how participants viewed themselves and interacted with others.

1.1: Adjusting to bodily changes required constant adaptation and physical effort

Participants described a range of physical changes, from fatigue and restricted mobility to ongoing concerns about odor or leakage. Routine activities that previously required little thought had to be adapted and managed more cautiously to avoid pain or embarrassment. For some, these challenges eased over time as they learned new routines, while others continued to face regular disruptions in daily functioning.

“When you wear the stoma bag for the first time, you feel it on your body it feels like a problem at first because, basically, a stoma bag has a pouch that sticks to your skin, and it feels like there’s a glue on your body.” (Male, 60 years)

“I constantly feel weak and lack strength.” (Female, 58 years)

“Eating habits change; there are things I can’t eat in the morning when I go to work because they cause a lot of gas.” (Female, 30 years)

The stoma was described as a burden that created a constant need to monitor their bodies, manage their energy, and adjust routine behaviors, even in the simplest aspects of daily life.

1.2: Emotional distress and shifts in self-perception accompanied the stoma experience

The emotional adjustment to the stoma often felt as taxing as the physical one, particularly in the early weeks and months. Participants spoke of feeling unsettled in their own bodies and reluctant for others to see or know about the stoma, leading to periods of withdrawal or emotional strain.

“Sometimes you accept that these are experiences you had to go through; other times, you reflect on them and feel pain and sadness that almost overwhelms you.” (Female, 30 years)

“It has caused depression; I no longer make long-term plans. It affects my mind: if I sit among people in meetings or at the market, I feel it might leak. I never feel at ease. Sometimes it gives me severe headaches; had I known before, I might not have agreed to the surgery. It’s a physical issue but also a mental one.” (Male, 60 years)

The participants described the experiences as an internal journey that gradually moved from discomfort and fear toward emotional adjustment and self-acceptance, often marked by setbacks and ongoing vulnerability.

1.3: Experiences of limited social engagement was characterized by self-imposed stigma, fear of exposure, and withdrawal from community life

Participants described how fears of odor, leakage, and stoma bag detaching led to a strong sense of self-imposed stigma. Even without direct judgment from others, they anticipated embarrassment, making public spaces feel unsafe. Because they could not afford timely replacements, many participants were forced to use their stoma bags beyond their intended duration, which increased the risk of leakage, contributing to their choice to stay home. As a result, many withdrew from social activities and self-isolated - not due to external stigma, but because of their internal fears.

"You feel ashamed because of the bad smell you have around people. Sometimes the colostomy outflows, and you feel embarrassed. You have a bad odor even when you maintain good hygiene...You feel like you're losing your mind. You lose hope in life. Because it happens unexpectedly, anytime, without warning. It leaks whenever it wants. You constantly worry, wondering what you would do if it burst in public. Sometimes the colostomy bag falls off after a few days; you end up using one for about 3–4 days because you can't afford to buy them daily, so you avoid going out among people." (Male, 47 years)

Their internalized stigma and fear contributed to self-isolation, significantly reducing participation in community and social life.

1.4 Having a stoma negatively impacted the intimate relationships

Participants' experiences revealed that sexual activity and intimacy were influenced by a combination of physical and psychological factors following stoma surgery. Even though some reported being informed by doctors that

sexual activity was medically permissible and continued without difficulty, most described a gradual decline in sexual desire or even complete withdrawal due to discomfort, odor concerns, or ill-informed medical advice. Emotional and existential factors - such as illness burden, fear of death, and religious convictions - also contributed to diminished sexual drive or decisions to avoid remarriage.

"It [sex] happens …but when you start thinking about dying and wondering what you'll do, the sexual drive is no longer there" (Male, 60 years)

"I don't have sex with my wife because of the bad odor." (Male, 47 years)

For one participant, the lack of sexual activity was due to medical advice from the doctor.

"It's not possible, they [doctors] told me not to …also I don't want it…we live separately" (Female, 72 years)

Participants described a broad range of experiences related to intimacy and sexual relationships. Their accounts indicated that both physical factors associated with the stoma and emotional responses to living with it shaped these aspects of their lives.

Theme 2: Persistent supply shortages and financial burden made stoma care unsustainable for most patients

Supply shortages and financial burden were captured under four sub-themes. Participants consistently described managing a stoma as a daily challenge shaped not only by the medical demands of care but by the availability and affordability of basic supplies. Gaps in the health system, coupled with high cost and limited distribution, meant many patients were left improvising or rationing essential materials. The strain was not only physical but also emotional and financial, with participants expressing frustration, helplessness, and a sense of abandonment as they navigated systems that were not built to support their long-term needs.

2.1: Unreliable access to stoma bags disrupted consistent self-care

Participants described stoma bag access as highly unpredictable, with supplies often running out unexpectedly and forcing them to make repeated trips - sometimes across multiple facilities or even to other towns. Stockouts were common, and the limited number of bags provided at each visit rarely matched their actual needs. Geographic disparities further compounded the problem, as those living outside urban centers faced longer travel times and greater uncertainty. As a result, many patients lived in constant worry about whether their supplies would last even a few days. As a result, maintaining hygiene and dignity became a stressful and uncertain process for many.

"They give me enough [stoma bags] for 15 days, but when they run out I have to travel to Kigali, and sometimes I do not find them even after going twice." (Male, 68 years)

"They gave me a few materials, but they often say they're out of stock. When I run out, I just use clean pieces of cloth." (Female, 72 years)

2.2: Improvised or reused materials were used in place of proper stoma supplies

Participants explained that when stoma bags were unavailable or insufficient, they were forced to improvise with whatever materials they had at home. Some used items like notebook paper to create a barrier under a reused bag, while others resorted to cloths when their limited supplies ran out. These improvisations were not choices but necessities created by chronic shortages, highlighting how gaps in access pushed patients to rely on makeshift solutions that offered minimal protection or comfort.

"I buy notebooks, use the pages, and then put a bag on top, securing it so it does not reach my clothes." (Female, 45 years)

“When I don’t go to the hospital to get supplies, or when the ones [stoma bags] they give me are too few and get used up, I use cloths.” (Female, 65 years)

The need of adopting these strategies also has emotional consequences. As the ostomates tried to improvise and conceal their problem, they feel exposed, anxious, and ashamed, particularly as they tried to conceal odors or leakage.

2.3: The combined costs of supplies, transport, and healthcare led to long-term financial strain

Participants described that living with stoma was an ongoing financial pressure that extended beyond the price of the bags themselves. Recurring costs for hospital visits, transport - often over long distances - and occasional lodging made routine care difficult to sustain. These ongoing expenses turned stoma care into a long-term economic burden that weighed heavily on both patients and their families.

“I even missed one of my hospital appointments because I didn't have the means to travel.” (Male, 68 years)

“Butaro often doesn’t have colostomy bags, so I go to Faisal or CHUK where I can get them with RAMA. Coordinating tickets [bus fare], lodging, and having someone accompany me is very stressful.” (Male, 65 years)

The economic burden extended beyond direct medical cost and affected livelihood, independence, and long-term planning.

2.4: Limited institutional support forced patients to depend on charity or personal networks

Although some organizations provided intermittent assistance, participants described institutional support as fragmented and unreliable, making it difficult to access essential documents, transport allowances, or regular stoma supplies. Even when such assistance existed, it was inconsistent or conditional, leaving patients feeling overlooked

and unsupported within the broader health system. Because formal systems, including CBHI, often failed to meet their needs, many turned to personal relationships, and individual benefactors for help.

"At the sector office, they were unable to give me the transport allowance to go to the district and get my medical card signed, which I need in order to receive treatment for this fourth year since my illness began... It would be helpful if you could represent us, for example at our local hospitals, so that we could receive supplies like these closer to us, since this is the life I now have to live" (Female, 58 years)

"There was a doctor who performed my surgery in Kibogora...who would sometimes help me and send small supplies through benefactors. But now, they no longer provide that support, so that assistance has stopped." (Female, 30 years)

The gap in having a consistent and long-term stoma care system led participants to rely on goodwill and informal support networks.

Theme 3: Participants adopted coping strategies grounded in acceptance, spirituality, and social support

Participants described coping as a gradual process, shaped not just by time but by intentional efforts to reframe their situation, reconnect with sources of meaning, and draw on support from others. While the stoma introduced profound physical and emotional challenges, many participants spoke of resilience that emerged through accepting their reality, practicing faith, and leaning on people they trusted. Over time, coping shifted from an internal struggle toward a shared effort of adapting, enduring, and reclaiming parts of their lives and identities.

3.1: Acceptance and a positive mindset helped ease emotional distress

For many participants, acceptance and embracing the reality of the stoma played an important role in reducing emotional strain. Rather than resisting or denying the change, participants described a conscious shift from fear and

sadness toward peace or renewed purpose. Acceptance was closely linked to feelings of gratitude for survival and the ability to keep living and often emerged as a positive reframing of their tragedy as a way to cope and move forward withe greater emotional stability.

"However, with time, we gradually accepted it, reminding ourselves that as long as we were still breathing, there was hope." (Female, 58 years)

"I'd tell them to accept it. After all, if you're seriously sick, it's better to live with a colostomy and survive for some more time than to die today." (Male, 65 years)

Acceptance not only reduced stress but also motivated participants to rebuild routines, re-enter social spaces, or resume work, even if adjustments were needed.

3.2: Faith and spirituality provided hope and comfort during adaptation

Spiritual belief emerged as a powerful coping mechanism, especially during moments of uncertainty or fear. Many participants interpreted their illness and stoma as part of a divine plan, which allowed them to see it not as a punishment but as a continuation of their purpose in life. Prayer, scripture, and faith-based reflection helped stabilize emotions and replace despair with hope and direction. Spiritual convictions also reinforced resilience, reminding individuals that their challenges were not beyond God's awareness or care.

"God is alive. What I know is that I still have a purpose; things that God has entrusted me to do before I die. I keep reminding myself of that and say, faith gives life." (Female, 45 years)

“Even before my illness, I relied strongly on the Scripture that says nothing will happen to a person that surprises God. I held firmly to that, knowing that nothing can take someone by surprise. It is important, therefore, that in life’s journey we face challenges, difficulties, and illness with acceptance and resilience.” (Female, 58 years)

These accounts show how spirituality grounded participants emotionally and allowed them to see themselves as more than their diagnosis, offering meaning, comfort, and strength throughout their adjustment to living with a stoma.

3.3: Practical and emotional support from family, peers, or close friends others made coping manageable

Social support played a central role in helping participants adjust to life with a stoma. For some, family members offered hands-on help - cleaning, buying supplies, or assisting with travel, making daily management less overwhelming. For others, support came through understanding and acceptance from loved ones or from peers facing similar challenges. Speaking with other stoma patients helped normalize the experience and strengthened resilience, while nonjudgmental care from spouses or close friends countered feelings of rejection.

“After experiencing this [stoma], I tried to accept my situation. I have continued to accept it up to today. I don’t overthink it or let it drive me into deep despair. For example, when I go to the hospital and see other patients in similar situations, talking with them makes me realize that I am not the only one facing this problem, which helps me accept it and be resilient.” (Female, 58 years)

“My father didn’t accept it well, and some people discriminated against me. But my wife accepted it fully.” (Male, 34 years)

“But at least I have two people who visit me often and know my situation. Even though they know, they don’t despise me; they love me.” (Female, 30 years)

Where such support was present, coping felt less like a private burden and more like a shared journey. However, participants also noted that this kind of support was uneven, and that stigma or lack of awareness sometimes made social connections more difficult.

CHAPTER 5: DISCUSSION

5.1 Overview

This mixed-methods study examined the prevalence, characteristics, and lived experiences of individuals with intestinal stomas in Rwanda. Quantitative data from 509 abdominal-surgery records provided a national overview of stoma formation, while qualitative interviews with eleven long-term ostomates explored physical, psychological, social, and economic experiences. Together, the two studies illustrate how clinical, structural, and personal factors interact to shape outcomes for patients living with stomas. This approach allowed both numerical patterns and embodied lived realities to be interpreted together, hoping to provide a clearer understanding of not only who receives stomas in Rwanda, but how these individuals navigate their altered bodies, daily routines, and social environments.

5.2 Prevalence and Etiology of Stoma Formation

This study found that 12% of all abdominal surgeries in 2024 from selected hospitals in Rwanda resulted in stoma formation. Interpreting this figure requires caution because neither Rwanda nor neighboring countries have national or multicenter data on stoma prevalence. Existing studies from East Africa - including case series from Ethiopia (Engida et al., 2016) and Tanzania (Massenga et al., 2019) - describe indications and outcomes but do not report the proportion of all laparotomies resulting in stoma creation. Because these single-center studies lack denominators, they cannot be directly compared with the present estimate. The limited regional evidence highlights a broader gap in epidemiological reporting and underscores the contribution of this study as one of the first system-wide assessments of stoma formation in Rwanda.

Although benign obstruction accounted for the largest absolute number of cases, malignancy represented the highest proportional likelihood of resulting in a stoma; 42% of patients with colorectal cancer received a diversion, compared with 12% for benign obstruction, and 10% for perforation or leak. This pattern indicates that stoma creation remains a key management strategy for advanced or obstructive cancer, consistent with Ugandan data where 40% of all adult ostomates had malignancy as the primary indication (Ssewanyana et al., 2021). In Rwanda,

delays in symptom recognition and presentation often result in late-stage colorectal cancer that cannot be resected primarily, leaving diversion as the safest option. Interestingly, no trauma-related stomas were documented in the 2024 dataset. Although African data are scarce, a recent study from Yemen found that most colonic trauma cases were managed with primary repair rather than diversion (Al-Amy et al., 2025) .This suggests that not all emergency bowel injuries routinely result in stoma formation, but the true regional pattern remains unclear due to limited evidence. It also aligns with evidence that many trauma-related stomas, when created, tend to be temporary and reversed early, reducing their visibility in routine surgical registers (Massenga et al., 2019; Ndayizeye et al., 2016).

The difference between referral and L2THs further illustrated systemic capacity gaps. L2THs recorded a stoma rate of 21.8% compared with 8.8% in referral facilities. This pattern likely reflects persistent delays in seeking, reaching, and receiving timely surgical care, a challenge well-documented in LMIC surgical systems using the Three Delays Framework (Bagguley et al., 2019). Patients often arrive at L2THs after prolonged illness or partial obstruction, requiring emergency surgery before transfer options are available. Limited diagnostic imaging, pathology, and specialist colorectal teams constrain the feasibility of primary restorative surgery. Similar findings in Rwanda where 63% of peritonitis cases were emergencies managed without restoration of continuity (Ndayizeye et al., 2016). An additional explanation may be the growing presence of general surgeons in L2THs with evidence showing that hospitals with an on-site general surgeon perform substantially more complex emergency procedures (Mpirimbanyi et al., 2017). This expanding workforce may mean more emergency and obstructive cases are definitively managed locally rather than referred upward, thereby increasing the proportion of stomas created at district level in the L2THs. Collectively, these quantitative patterns align with participants' narratives of delayed presentation and emergency decision-making, reinforcing how structural constraints shape both surgical outcomes and lived experience.

In high-income countries, by contrast, stomas are most often created electively for colorectal cancer, diverticular disease, or inflammatory bowel disease, conditions detected early through screening programs (Albulescu et al.,

2023; Hendren et al., 2015). In the United Kingdom, for example, nearly 70% of ostomies follow planned oncological resection, while less than 10% result from acute obstruction or perforation (Hendren et al., 2015). The difference underscores how Rwanda's stoma epidemiology is driven by late presentation rather than disease type. Variations in dietary fiber intake, gut microbiome profiles, and genetic factors, each documented contributors to diverticulitis and inflammatory bowel disease, likely account for the comparatively low occurrence of these conditions in African populations (Hodges & Kelly, 2020; Ng et al., 2020). Rwanda's growing number of colorectal cancer cases, consistent with broader increases observed cross sub-Saharan Africa, therefore represents a shift toward non-communicable surgical disease within a system still oriented to emergencies (WHO, 2022).

5.3 Physical and Functional Challenges

Participants described fatigue, dietary modification, and the need for careful planning to prevent leakage and odour. These findings align with a previous study that noted that daily adjustment and bodily monitoring are central to long-term adaptation (Capilla-Díaz et al., 2019). These changes also reflect core ideas from embodiment theory, where disruptions to the body require individuals to renegotiate their sense of physical self, a process well-described in stoma research showing that patients often experience their bodies as unfamiliar or intrusive after surgery (Thorpe et al., 2016). In contrast, short-term complications such as prolapse, retraction, or peristomal excoriation - reported in up to 25% of Ethiopian patients (Engida et al., 2016) and 32% in a multinational analysis (Albulescu et al., 2023) - were rarely mentioned in this study. This difference likely results from the sample composition: all interviewees were long-term ostomates, meaning early postoperative complications had either resolved or were not recalled in detail. The smaller sample size may also have limited the diversity of complications captured.

Participants' accounts of sexual and intimate-relationship changes add an underexplored dimension to Rwandan literature. Some continued sexual activity without difficulty, while others reported reduced desire, medical advice to abstain, or avoidance due to odour and embarrassment. Similar reductions in sexual function have been observed among 58% of Turkish and 63% of Brazilian ostomates (Ayaz-Alkaya, 2019; Valadares de Oliveira et al., 2018).

Emotional and existential concerns, including fear of death and religious beliefs, further influenced attitudes toward intimacy and remarriage. Sexual and intimate relationship changes reported by participants align closely with patterns described in global stoma literature. Some continued sexual activity without difficulty, while others described reduced desire, avoidance due to odour or embarrassment, or uncertainty about how partners perceived them. These experiences reflect broader evidence that stoma formation can alter body image, confidence, and sexual expression, with many patients reporting feeling less attractive or hesitant to engage in intimacy (Vural et al., 2016) .These findings illustrate the process of adaptation to bodily change, a psychological and behavioral realignment well documented in chronic illness literature and in recent trauma history (Capilla-Díaz et al., 2019).

5.4 Psychological and Social Dimensions

Emotional responses during recovery ranged from shock and denial to eventual acceptance. Fear of public embarrassment and uncertainty about body image were frequently reported. These patterns align with findings from stoma research showing that stoma formation often requires a redefinition of identity and self-perception (Capilla-Díaz et al., 2019) .In Uganda, 72% of ostomates experienced moderate to severe anxiety during the first six months after surgery, reflecting similar early emotional distress (Ssewanyana et al., 2021) . Comparable emotional trajectories were evident in this study, though participants also described developing coping mechanisms such as selective disclosure and humor to navigate social interactions. These qualitative insights complement the quantitative finding that older adults and patients with malignancy were more likely to receive stomas, as these groups may face greater emotional and existential disruption in adjusting to long-term bodily change.

Stigma remained a significant barrier to social participation. Participants avoided public gatherings or travel due to fear of leakage or lack of private facilities. Comparable findings from Ethiopia showed that 60% of respondents limited their mobility for the same reason (Aboma & Kaba, 2023) . Importantly, many participants in this study described primarily self-imposed stigma - anticipatory shame rather than direct discrimination. This pattern aligns with evidence showing that ostomates often withdraw socially not because of explicit rejection, but due to internalized fear of leakage, odour, or embarrassment (Aboma & Kaba, 2023; Ayaz-Alkaya, 2019; Valadares de

Oliveira et al., 2018). In the absence of professional counseling or peer groups, patients relied mainly on family and faith communities for support. This gap reflects a broader shortage of psychosocial services within surgical follow-up programs. The lack of trained ostomy nurses or counselors means emotional care is often informal, depending on the initiative of individual clinicians.

5.5 Economic and Structural Barriers

The data demonstrates that stoma care imposes ongoing financial strain. Although the community-based health insurance scheme (Mutuelle de Santé) theoretically covers ostomy supplies, participants reported inconsistent availability and stockouts. Many purchased bags privately at costs ranging from 3,500 to 5,000 RWF each, a sum that represents a substantial proportion of the typical household income given that the median monthly income of paid workers was 43,333 RWF and the national poverty rate stood at 27.4% (NISR, 2025). Frequent travel to Kigali for supplies compounded expenses, especially for patients living on subsistence incomes. Improvisation using plastic or paper materials was common, mirroring practices reported among 41% of Brazilian ostomates who faced similar supply shortages (Valadares de Oliveira et al., 2018).

Institutional and geographic disparities contribute further to inequity. L2THs, where emergency surgeries are common, often lack steady procurement channels for consumables, a pattern consistent with broader surgical capacity (MOH, 2018). Referral hospitals may receive donations through international partnerships, but distribution beyond urban centers remained limited. Evidence from multiple countries shows that postoperative outcomes worsen with increasing distance from tertiary hospitals, creating financial pressures that can destabilize households, as seen in participants who sold land or reduced food expenditure to cover medical costs (Rickard et al., 2020). These accounts confirm that financial risk protection remains incomplete despite Rwanda's high insurance coverage rate. These structural patterns help explain why the economic burden described in interviews was so pronounced among rural and low-income participants, linking geographic inequity in supply chains directly to lived financial strain.

5.6 Coping, Acceptance, and Adaptation

Despite substantial hardship, participants demonstrated adaptive resilience through acceptance, faith, and social support. Acceptance was frequently described as a gradual process that enabled emotional recovery and re-engagement with routine life. This finding is consistent with evidence showing that acceptance is a core predictor of long-term psychological adjustment among ostomates, contributing to better quality of life and lower emotional distress (Capilla-Díaz et al., 2019). This progression reflects well-established psychological models of adaptation. Frameworks such as the Kübler-Ross model describe how individuals move from initial shock and denial toward eventual acceptance when confronted with major life changes . Contemporary Acceptance and Commitment Therapy (ACT) research also highlights acceptance as a core mechanism that helps individuals acknowledge difficult bodily changes while continuing to engage in meaningful activities, thereby improving emotional adjustment (Graham et al., 2016). These models help explain why participants who embraced acceptance described greater emotional stability and improved daily functioning.

Faith similarly served as a coping resource. Participants interpreted the stoma within a spiritual framework, a pattern supported by evidence showing that higher spiritual well-being is associated with better psychological adjustment among ostomy patients (Ayik et al., 2019) . In addition, Pargament's theory of religious coping highlights how spiritual meaning-making can reduce distress and strengthen resilience during health-related adversity, a pattern supported by recent evidence showing that religious meaning systems are associated with improved emotional adaptation in illness contexts (Krok et al., 2021). These models help explain why participants who embraced acceptance, whether through psychological or spiritual strategies, described greater stability and improved daily functioning. Social support also played a crucial role in coping. Family members and peers provided practical assistance with cleaning, transportation, and supply collection, as well as emotional reassurance. Strong social networks are known to significantly reduce depression and anxiety among ostomy patients, by nearly half in some studies (Farahani et al., 2022). In Rwanda, where formal stoma rehabilitation services are limited, such informal networks form the primary support system. These findings mirror broader evidence that peer

comparison, shared experience, and supportive relationships foster resilience and help normalize life with a stoma (Ayik et al., 2019; Capilla-Díaz et al., 2019; Farahani et al., 2022).

5.7 Study Limitations and Challenges Encountered.

This study was the first in Rwanda to examine national prevalence alongside the lived experience of individuals with stomas, providing an important foundation for understanding the scope and impact of stoma care in the country. However, the findings should be interpreted with caution in light of some limitations. First, the reliance on retrospective hospital data meant that the quantitative analysis depended on existing theatre registers, which were sometimes incomplete, inconsistently recorded, or lacked standardized reporting formats across facilities. These limitations affected the depth of available demographic and clinical variables and restricted subgroup analyses, particularly for factors such as regional distribution, insurance status, and clinical outcomes. Although data verification and double entry minimized errors, the accuracy of certain records ultimately relied on how carefully information had been documented at the facility level.

Second, the qualitative sample was relatively small and homogeneous, consisting of eleven participants who had all undergone stoma surgery for colorectal cancer. This focus provided valuable, in-depth insights into cancer-related stoma experiences and long-term adaptation. This also reflects clinical realities where most non-malignant conditions typically require temporary or reversible stomas and cancer-related procedures more often result in permanent stomas. Consequently, while the narratives reveal important cross-cutting physical, emotional, and social challenges, they may not fully capture variations in lived experiences for people with non-malignant conditions or trauma-related stomas. While this is consistent with regional trends toward primary repair for bowel trauma and early reversal of temporary stomas, prospective data would help confirm whether this absence reflects true practice patterns or documentation gaps.

5.8 Implications for Policy and Practice

The findings signal a clear need for Rwanda to strengthen its stoma care system through integrated clinical, financial, and social interventions. Several policy directions are worth considering. First, integrating stoma bags and skin barriers into the national essential medicines and supplies list would help guarantee predictable procurement and delivery to health centers and L2THs. This could reduce out-of-pocket spending and the need for improvisation, improving hygiene, and dignity for patients. Broader analyses of surgical supply systems in sub-Saharan Africa also demonstrate that incorporating essential consumables into national lists reduces stockouts and improves equitable access (Rickard et al., 2020).

Second, establishing follow-up clinics and peer-support groups led by trained stoma nurses or clinical officers could provide structured counselling and practical teaching. Evidence from Brazil and Europe shows that such programs lower complication rates, reduce anxiety, and improve self-care confidence (Capilla-Díaz et al., 2019; Valadares de Oliveira et al., 2018). Aligning these interventions with Rwanda's decentralized NCD care model would address the psychosocial and educational gaps highlighted in this study. Third, the integration of psychosocial support and mental health screening into existing non-communicable disease pathways could better address the emotional burden of patients, especially cancer survivors. Recent evidence shows that psychosocial distress and unmet supportive care needs remain common long after treatment ends, underscoring the importance of routine psychological screening and structured survivorship support to improve quality of life among colorectal cancer survivors (Andreu et al., 2022). Given the disparities between L2TH and referral hospitals, procurement systems should prioritize rural facilities to reduce geographic inequity in access to ostomy supplies. Policy interventions should also incorporate psychosocial and embodiment-informed support, recognizing that adjustment to stoma care extends beyond clinical management to include identity, self-perception, and social reintegration. Future research should explore the health economic implications of stoma care by comparing its long-term costs with existing financial protection mechanisms, such as health insurance, and by supporting initiatives for local production of affordable stoma bag alternatives.

CHAPTER SIX: CONCLUSION AND RECOMMENDATIONS

6.1 CONCLUSION

This mixed-methods study provides one of the first empirical examinations of both the prevalence of intestinal stoma formation and the lived experiences of individuals living with stomas in Rwanda. Quantitative findings showed that 12% of abdominal surgery patients received a stoma during the study period. Stoma formation was more common in older adults and patients with colorectal malignancies, consistent with global trends where malignancy remains a leading indication for permanent stoma creation. No trauma-related stomas were observed in the 2024 dataset, which is consistent with regional evidence that bowel trauma is increasingly managed with primary repair and that any trauma-related stomas are usually temporary and reversed early. L2THs also had higher proportions of stoma formation, likely reflecting emergency presentations and delayed referrals that limit the feasibility of restorative surgery. In addition, the growing presence of general surgeons at district level in L2THs may be contributing to more complex emergency cases being managed locally rather than referred, which helps explain the higher proportion of stomas observed in these hospitals.

Qualitative findings complemented these patterns by illustrating how physical, psychological, and socioeconomic challenges intersect in daily life for long-term stoma patients. Participants described persistent difficulties with supply access, financial strain, altered body image, and reduced social participation. Many of these challenges were shaped less by overt discrimination and more by internalized or self-imposed stigma, particularly fear of leakage, odour, or embarrassment in public spaces. Although many had adjusted to stoma care routines, emotional vulnerability and stigma persisted, particularly around intimacy and community interaction. Coping was strongly mediated by acceptance, faith, and practical support from family or peers. These responses are consistent with adaptation and resilience frameworks, in which individuals gradually integrate chronic bodily changes into their routines and identities while drawing on social and spiritual resources to sustain emotional wellbeing. These findings underscore the dual clinical and psychosocial burden of living with a stoma in a resource-limited setting. They also highlight how health-system factors - such as geographic disparities in supply distribution, variable

surgical capacity between L2TH and referral hospitals, and limited access to psychosocial support - interact with individual experiences of embodiment, identity, and stigma to shape long-term outcomes for ostomates in Rwanda.

6.2 RECOMMENDATION

The Ministry of Health, in collaboration with hospital procurement units, should establish a reliable and consistent supply chain for ostomy supplies to alleviate the financial burden on patients. Priority should be given to ensuring that L2THs and rural facilities receive regular deliveries, so that patients are not forced to travel long distances or improvise with unsafe materials when stockouts occur.

Investment should be directed toward the local production of affordable stoma bag alternatives to enhance accessibility and sustainability. Such initiatives should be accompanied by quality standards and end-user testing with ostomy patients to ensure that locally produced products are safe, acceptable, and durable.

Psychosocial support should be integrated into post-surgical follow-up care. Hospitals should be encouraged to incorporate counselling and peer-support programs into routine services, creating safe spaces where patients and families can discuss challenges and share coping strategies. This could include training stoma nurses or designated focal persons in basic psychosocial care, as well as facilitating support groups where patients can learn from others living with a stoma and reduce feelings of isolation and self-stigma.

Clinical training, early detection, and timely referral systems should be strengthened to reduce delays in healthcare seeking and improve patient outcomes. This includes reinforcing pathways for earlier recognition and management of colorectal cancer.

Finally, the establishment of a national stoma registry is recommended to facilitate systematic documentation of cases and outcomes, thereby informing evidence-based planning and resource allocation. Future research should build on this registry to prospectively examine indications, reversals (including trauma- and benign-related stomas), complication rates, quality of life, and economic impact.

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APPENDICES

Appendix 1: Consent Form

Part I: Informationa and Consent Form - English

Participant ID: _____

Project title: *Prevalence of Intestinal Stomas in Rwanda and the Experiences of Individuals Living with Them: A Mixed-Methods Study.*

Study population: People living with long term intestinal stomas for more than 6 months

Version date: November 2024

You are invited to participate in a research project titled *"Prevalence of Intestinal Stomas in Rwanda and the Experiences of Individuals Living with Them: A Mixed-Methods Study."*

The purpose of this study is to assess the prevalence of intestinal stomas in Rwanda and explore the experiences of individuals living with them. By participating, you will contribute to a better understanding of the challenges faced by stoma patients, which will help inform policies and programs aimed at improving their care and quality of life.

If you choose to participate, you will be asked to provide information about yourself, your medical history, and your experiences living with a stoma. You may also answer questions about the economic, social, and emotional impacts of your condition.

Participation is entirely voluntary. If you feel uncomfortable at any point during the interview or discussion, you can request to pause or stop. You are free to leave the study at any time without any consequences or impact on your medical care.

To protect your privacy, your name or any identifiable information will not be collected. All information you provide will be kept confidential and securely stored in password-protected files or locked storage. Only the research team will have access to this information, which will be destroyed after 10 years.

Your participation in this study is greatly valued. If you have any questions or concerns, please feel free to contact the research team at irb@ughe.org. Thank you for considering participating in this important research.

Statement of consent

Your agreement indicates you acknowledge that:

- You have understood the content of this form.
- You have had the opportunity to ask questions and received answers that were satisfactory.
- You agree to participate in this project.

_____ _____

Full name and signature of the participant Date and location

_____ _____

Full name and signature of the person requesting consent Date and location

Part II:Inyandiko Isobanura Inasaba Uburenganzira bwo Gukora Ubushakashatsi

Umubare uranga utanga amakuru: _____

Muvandimwe ugiye kwifatanya natwe mu bushakashatsi,

Urarikiwe gutanga umusanzu wawe mu mushinga w'ubushakashatsi ugamije kurebera hamwe ingano ya sonde zo mu mara ndetse n'imibereho y'abantu babana nazo.

Niba wemeye kwifatanya natwe, turaza kukubaza ibibazo byerekeye kubuzima bwawe nk'umuntu ubana na sonde yo mu mara, by'umwihariko nk'umuntu ubanye nayo mu gihe kirekire kirenze umwaka umwe. Twizerako amakuru uduha hano, azifashishwa mu guteganya ingamba zizajya zifashishwa n'impuguke muri gahunda zifasha abanda nkamwe mu kugira ubuzima buzira umuze.

Nta kibazo gikomeye kizwi gishobora kukubaho bitewe no kuba wifatanyije natwe muri ubu bushakashatsi.

Ariko igihe wumvishe ubangamiwe mu gihe uri kuganirizwa, ikiganiro gishobora gusubikwa kikimurirwa ikindi gihe cyangwa kigahagarikwa burundu.

Ku bushake bwawe, wemerewe kureka kwifatanya natwe muri ubu bushakashatsi.

Ubushakashatsi kandi, ntabwo buzakusanya amakuru yerekeye amazina cyangwa se n'indi myirondoro yawe bwite. Amakuru ari butangwe, tubijeje ko atazigera asangizwa n'umuntu uwo ari we wese, keretse abagize itsinda ry'ubushakashatsi. Nimubitwemerera turafata amajwi kugirango tuzabone uko twandika ibyo twaganiriye twitonze. Nyuma yo kuyakoresha, amakuru yose azabikwa mu bubiko bwizewe, no muri mudasobwa irinzwe n' ijambobanga. Amakuru azabikwa mu gihe cy'imyaka icumi, nyuma y'aho azasibwa.

Niba ufite ikibazo, ikifuzo, cyangwa igitekerezo kuri ubu bushakashatsi, wakohereza ubutumwa kuri konti ya imeyili (e-mail) irb@ughe.org.

Niba ugiye kwifatanya natwe mu bushakashatsi, wemeye ko;

- Wasobanukiwe neza ibiri muri iyi nyandiko

- Wagize amahirwe yo kubaza ibibazo waba wagize kuri ubu bushakashatsi, wahawe n’ibisobanuro bihagije.
- Wemeye kwifatanya natwe muri ubu bushakashatsi.

_____	_____
Izina n’umukono by’utanga amakuru	Itariki n’aho byakorewe
_____	_____
Izina n’umukono by’usaba amakuru	Itariki n’aho byakorewe

Appendix 2: Quantitative Data Collection Tool

Part I. Demographic Information

1. Gender (Male, Female, Other)
2. Age (Numeric, years)
3. District (Open ended)
4. Insurance (MUSA, Private, Out-of-pocket)

Part II. Clinical Information

1. Pre-operative Diagnosis (Open ended)
2. Procedure (Open ended)
3. Stoma type (Ileostomy, Colostomy, Both)

Appendix 3: Qualitative Interview Guide

Part I: English

Study Title: *Prevalence of intestinal stomas and challenges of individuals living with long term stomas in Rwanda: A mixed methods study*

Introduction:

Thank you for agreeing to participate in this study. We appreciate your time and willingness to share your experiences. The purpose of this interview is to understand your journey of living with a stoma, including the challenges you face and the coping strategies you use. There are no right or wrong answers - please feel free to share openly. Your responses will remain confidential.

Opening Question:

1. Can you describe your experience from the moment you first learned you would need a stoma?

Physical and Medical Challenges:

2. How has having a stoma affected your daily life and routine?
3. What kind of medical care or support have you received for your stoma?
4. Have you experienced any complications (e.g., infections, leakage, irritation)? How did you manage them?
5. How accessible are stoma care products (e.g., bags, skin barriers) for you?

Psychosocial and Emotional Impact:

6. How has living with a stoma affected your emotions and mental well-being?
7. Have you felt any stigma or discrimination because of your condition? Can you share an example?
8. How have your relationships with family, friends, or your community changed since getting a stoma?

Economic and Financial Impact:

9. Has having a stoma affected your ability to work or generate income? If so, how?

10. Are there financial challenges associated with managing your stoma? If yes, what are they?

Coping Strategies and Support Systems:

11. What strategies have you found helpful in coping with the challenges of living with a stoma?
12. Have you received any support from healthcare providers, family, or support groups? What was helpful, and what was lacking?
13. What advice would you give to someone newly adjusting to life with a stoma?

Closing Question:

14. Is there anything else you would like to share about your experience that we haven't discussed?

Part II: Kinyarwanda

Imfashanyigisho cy'ikiganiro cyimbitse

Umutwe w'Ubushakashatsi: Ikigero cy'abafite *sonde yo mu mara* n'ibibazo by'abantu babana na yo igihe kirekire mu Rwanda: Ubushakashatsi buhuza imibare n'ibyimbitse.

Intangiriro:

Murakoze kwemera kugira uruhare muri ubu bushakashatsi. Turabashimira igihe cyanyu n'ubushake bwo gusangiza ubunararibonye bwanyu. Intego y'iki kiganiro ni ukumenya urugendo mwanyuzemo mubana na *sonde yo mu mara*, ibibazo muhura nabyo ndetse n'uburyo mubicamo. Nta gisubizo cyiza cyangwa kibi gihari—mwisanzure musangize uko mubibona. Ibyo muzavuga bizaguma ari ibanga.

Ikibazo cyo Gutangira:

Mwashobora gusobanura uko mwiyumvise mumenya ko mugiye kugira *sonde yo mu mara*?

Ibibazo ku Mubiri n'Ubuvuzi:

- Ni gute *sonde yo mu mara* yahinduye imibereho yanyu ya buri munsi?
- Ni ubuhe bufasha bw'ubuvuzi mwahawe kuri *sonde yo mu mara* yanyu?
- Ni izihe ngaruka mwaba mwarahuye nazo zatewe na sonde (nko kwandura infeksiyo, kuva, kuribwa)? Mwabigenje mute?
- Ibikoresho byifashishwa mu kwita kuri *sonde yo mu mara* (nk'udufuka, utuvuta two gusiga) bibageraho byoroshye?

Ingaruka ku Mitekerereze n'Imibereho:

- Kubana na *sonde yo mu mara* byagize izihe ingaruka ku byiyumviro, amarangamutima ndetse no ku buzima bwo mu mutwe?
- Hari aho mwigeze guhabwa akato cyangwa se guhezwa kubera uko mubayeho? Mwatanga urugero?

- Umubano wanyu n'umuryango, inshuti, cyangwa se n'abandi mu bana muri rusange wahindutse gute kuva mwabana na *sonde yo mu mara*?

Ingaruka ku Bukungu:

- Kuba mufite *sonde yo mu mara* byagize ingaruka gute ku bushobozi bwo gukora cyangwa kwinjiza amafaranga?
- Hari ibibazo by'amafaranga bijyanye no kwita kuri *sonde yo mu mara*? Niba bihari, ni ibihe?

Uburyo bwo Kwihanganira Ibibazo n'Ubufasha:

- Ni ubuhe buryo mwabonye bubafasha mu kwihanganira ibibazo byo kubana na *sonde yo mu mara*?
- Mwigeze mubona ubufasha buturuka ku baganga, umuryango, cyangwa amatsinda yunganira? Ni iki cyabafashije, kandi ni iki cyaburaga?
- Ni iyihe nama mwaha umuntu ugiye gutangira kubaho na *sonde yo mu mara*?

Ikibazo cyo Gusoza:

Hari ikindi mwifuza gusangiza ku bunararibonye bwanyu tutavuze?

Appendix 4: Ethical Considerations

Ethical protections plan

Vulnerable Populations

This study involves individuals living with intestinal stomas, who may be considered a vulnerable population due to potential physical, psychological, and social challenges. Additionally, participants from rural areas or lower socioeconomic backgrounds may face compounded vulnerabilities related to limited healthcare access and social support. Special care will be taken to ensure their dignity, autonomy, and well-being throughout the study.

Assessment of Risks to Participants

The primary risks include potential emotional distress while recounting personal experiences and concerns about privacy. Participants may feel discomfort discussing sensitive topics such as stigma, body image, or intimate relationships. To mitigate these risks:

Participants will be informed that they can pause or withdraw from the study at any time without penalty (Appendix I). Interview questions will be approached sensitively, and research assistants are trained to respond empathetically to signs of distress. Access to psychosocial support services will be facilitated for participants who experience distress

Medical or Psychosocial Support

If any participant exhibits signs of psychological distress during or after the interview, they will be referred to appropriate psychosocial support services available within the healthcare facilities. Collaboration with local healthcare professionals will ensure that participants have access to counseling or other support resources as needed.

Information and Consent Process

A comprehensive informed consent process will be implemented to ensure participants fully understand the study objectives, procedures, and potential risks (Appendix I). Key steps include: Providing detailed information in depth about the study, in Kinyarwanda and/or English, including its purpose, methods, and how the collected data will be used and protected. Explaining participants' rights, including the right to withdraw at any stage.

Obtaining written consent from all participants before data collection begins. For those who cannot provide written consent, verbal consent will be documented.

Protection of Privacy and Confidentiality

Participants' privacy will be protected during data collection by conducting interviews in private settings. Confidentiality will be upheld by anonymizing data and using codes instead of identifiable information. No identifying details will be included in reports or publications.

De-Identification of Data

All data will be de-identified by assigning unique codes to participants. Identifiable information (e.g., names, contact details) will be stored separately from research data in a password-protected file accessible only to the principal investigator and authorized team members.

Safekeeping of Data

Data will be securely stored in password-protected digital systems and encrypted databases. Physical materials, such as consent forms, will be kept in a locked cabinet. Data will be retained for a period of ten years, in compliance with ethical guidelines, and then destroyed securely.

This ethical protection plan aligns with international research ethics standards and Rwanda's regulatory requirements to ensure the safety, privacy, and dignity of all participants.

UGHE IRB Approval + Amendment

University of Global Health Equity- Institutional Review Board

Notification of Approval

Ref: UGHE-IRB/2025/363

April 1, 2025

Protocol Title:	Prevalence of Intestinal Stomas in Rwanda and the Experiences of Individuals Living with them: A Mixed-Methods Study
Principal Investigator(s):	Mutesi Mukinisha
Protocol #:	363
Funding Source:	UGHE
Initial IRB Review Date:	24th January 2025
Initial Review Type:	Expedited review
Additional Review Dates:	25th March 2025
IRB Review Action:	**Approved**
Effective Date:	01st April 2025
Expiration Date:	31st March 2026

UNIVERSITY OF GLOBAL HEALTH EQUITY
P. O. BOX 6955, KIGALI, RWANDA
INSTITUTIONAL REVIEW BOARD
01 APR 2025
APPROVED
VALID UNTIL DATE SHOWN

Dear Mutesi Mukinisha

On March 25th, 2025, the University of Global Health Equity Institutional Review Board (UGHE IRB) approved your submitted study. **Please note that the approval for this protocol will lapse after one (1) year and must be renewed according to the procedures of the UGHE IRB.**

The IRB reminds you that you are responsible for fulfilling the following requirements:

- Changes, amendments, and addenda to the protocol or consent form (if applicable) must be submitted to the committee for review and approval, prior to activation of the changes.
- Only approved consent forms are to be used for the enrollment of participants.
- All consent forms signed by subjects must be retained on file, and are submitted to inspection, along with other project materials, during routine onsite visits or audits.
- Upon expiry of the approval, failure to apply for renewal will result in the suspension or termination of the study.
- The UGHE IRB must be notified at the closure of the study with a summary report.

Please contact the UGHE IRB via email at irb@ughe.org with any questions.

Sincerely,

Dr. Anselme Shyaka,
IRB Chair

UNIVERSITY OF
Global Health
EQUITY

Office of the Chair, Institutional Review Board
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Ref: UGHE-IRB/2025/363

Date: August 7, 2025

Notification of Approval of Protocol Amendment

Type of request:
[ ] Initial application
[ ] Exemption
[ ] Expedited
[√] Protocol amendment
[ ] Annual renewal
[ ] Other, specify .....

Dear Mutesi Mukinisha
Principal investigator

Re: Prevalence of intestinal stomas and challenges of individuals living with long term stomas in Rwanda: A mixed methods study

Reference is made to your request to amend the above-mentioned protocol, submitted to the University of Global Health Equity Institutional Review Board (UGHE-IRB).

On behalf of the Board, I am pleased to inform you that your amendment request has been approved. This approval is effective from August 7, 2025, to August 6, 2026.

As Principal Investigator, the UGHE IRB reminds you of the following responsibilities:

- Use only IRB-approved materials: Enrollment of participants must be conducted using the approved protocol, consent forms, and data collection tools.
- Submit changes for approval: Any changes, amendments, or addenda to the protocol or consent forms must be submitted to the IRB for review and approval before implementation.
- Maintain consent documentation: All consent forms signed by participants must be retained on file and made available for inspection during routine onsite visits or audits, along with other project-related materials.
- Notify the IRB at study closure: Upon completion of the study, a closure report summarizing the research must be submitted to the UGHE IRB.

Please contact the UGHE IRB at irb@ughe.org if you have any questions.

Sincerely,

Dr. Anselme Shyaka
Chair, UGHE-IRB

UNIVERSITY OF GLOBAL HEALTH EQUITY
P. O. BOX 6955, KIGALI, RWANDA
INSTITUTIONAL REVIEW BOARD
APPROVED
VALID UNTIL DATE SHOWN

MOH Authorization

REPUBLIC OF RWANDA

KIGALI, 14 APR 2025
N°20/ 1064 /DPMEHF/2025

MINISTRY OF HEALTH
P. O. BOX: 84 KIGALI
www.moh.gov.rw

Vice Chancellor, University of Global Health Equity (UGHE)
BUTARO

Re: Authorization to conduct research

Dear Vice Chancellor,

Reference is made to your letter dated March 7, 2025, requesting a support letter to allow your students **(batch 1)** to conduct research projects at various health facilities;

Based on the University of Global Health Equity (UGHE) - Institutional Review Board approval notifications provided to thirteen (13) research projects; I am pleased to inform you that the Ministry of Health has granted you authorization to conduct the thirteen research projects mentioned in the attached list of students.

Kindly, ensure that the results and the final reports are shared with the Ministry of Health upon the completion of the studies. We trust that the data will be used in full compliance with national ethical and data protection standards.

For further information or clarification, please don't hesitate to contact Mr. Jerome H. BUSHUMBUSHO via his email at Jerome.bushumbusho@moh.gov.rw or by Phone at **+250 785 420 300**

Sincerely,

MINISTRY OF HEALTH
"By Authority Delegation"

Dr. Muhammad SEMAKULA
HoD of Planning, M&E, and Health Financing

Cc:

- **Hon. Minister of Health**
- **Hon. Minister of State/MoH**
- **Permanent Secretary/MoH**

S/N	Name(s)	Project Titles	Health Facilities
1	Genereuse Irakoze Iradukunda Betty Kabarungi	Evaluating the Impact of Prophylactic Antibiotic Timing before Cesarean section on Surgical Site Infections (SSI) rates at Kirehe district Hospital.	Kirehe DH
2	Ndagije Clemence Ishimwe	Understanding Physicians' and Patients' Perspectives on the Adequacy of Pain Management Practices during Manual Vacuum Aspiration at a Rwandan District Hospital	Kacyiru District Hospital
3	Beula Igiraneza Eden Gatesi	Assessing Catastrophic health Expenditure on Burn Patients at a DH in Rwanda.	Kabgayi and Ruhengeri DH
4	Joyeuse Urujeni Alima Uwimana	Impact of Having a Preterm Infant on Maternal Health: A Study of Mothers with infants in Neonatal Care Units	Kacyiru and Ruhengeri Hospital
5	Jean Bertrand Aime Hakizimana Evergiste Singizwa	Assessing the Impact of Expert Mothers Program on Knowledge and Attitude towards Neonatal Danger Signs Among Post-Partum Mothers	Kirehe and Ruhengeri
6	Mutesi Mukinisha	Prevalence of stoma creation and lived experience of individuals living with stomas in Rwanda: A mixed methods study	All referral and provincial hospitals
7	Gloria Nishimwe Marlene Muhongerwa	Compliance with six critical perioperative infection prevention standards at Kacyiru Hospital, Rwanda	Kacyiru district hospital
8	Derrick Niyonkuru Heritier Mfura	Assessing the Patients' Satisfaction with Pharmacological Cancer Pain Management at two Cancer Centers in Rwanda	BL2TH and RMH
9	Axel Shimwa	Experience of Alcohol Use Disorder Patients in accessing mental health care in Rwanda	Ndera Neuropsychiatric Teaching Hospital
10	Materne N Kayumba Gislaine Mutatsineza	Comparison of Self-Collected vs Medic-Collected Vaginal Swabs for Detecting Oncogenic HPV in Cervical Cancer Screening Among Rwandan Women	RBC Screening Sites
11	Florentine Uwineza	Compliance in Handling Cytotoxic Cancer Medication at Butaro Level II Teaching Hospital According to Guidelines	BL2TH
12	Jean Eric Niyitanga	Patient loss to follow in NCD care	Rwinkwavu
13	Olive Uwamahoro, Olive Munthali	Adolescents' Experience of Gender-Based Violence: A Qualitative Study in Burera.	Isange One stop center

Hospital Approvals

1. CHUK

CENTRE HOSPITALIER UNIVERSITAIRE
UNIVERSITY TEACHING HOSPITAL

Quality Health Care
Training & Research

Ethics Committee / Comité d'éthique

22nd Aug,2025 *Ref.:EC/CHUK/140/2025*

Review Approval Notice

Dear Mutesi Mukinisha,

Your research project: ***"Prevalence of intestinal stomas and challenges of individuals living with long term stomas in Rwanda: A mixed methods study "***

During the meeting of the Ethics Committee of University Teaching Hospital of Kigali (CHUK) that was held on 22nd Aug,2025 to evaluate your request for ethical approval of the above mentioned research project, we are pleased to inform you that the Ethics Committee/CHUK has approved your research project.

You are required to present the results of your study to CHUK Ethics Committee before publication by using this link:www.chuk.rw/research/fullreport/?appid=1638&&chuk.

PS: Please note that the present approval is valid for 12 months.

Yours sincerely,

Dr Emmanuel Rusingiza Kamanzi
The Chairperson, Ethics Committee,
University Teaching Hospital of Kigali

ETHICS COMMITTEE
CHUK

Scan code to verify.

" University teaching hospital of Kigali Ethics committee operates according to standard operating procedures (Sops) which are updated on an annual basis and in compliance with GCP and Ethics guidelines and regulations "

Web Site : www.chuk.rw ; B.P. 655 Kigali- RWANDA Tél.: 00 (250) 252575462. E-Mail: chuk.hospital@chuk.rw

2. CHUB

chub.rw

CHUB
University Teaching Hospital of Butare

OFFICE OF DIRECTOR GENERAL

Huye, 04/08/2025
Ref: CHUB/DG/NC/08/1126/2025

Mrs Mutesi Mukinisha
Email; mutesi.mukinisha@student.ughe.org
Phone number: 0783285359

Dear Mutesi

Re: Your request for data collection

Reference made to your letter requesting permission to collect the data within the University Teaching Hospital of Butare for your research project entitled:" Prevalence of Intestinal Stomas in Rwanda and the Experiences of Individuals Living with Them: A Mixed-Methods Study" based on the ethical approval *No: UGHE-IRB/2025/363*.

We are pleased to inform you that your request has been accepted. Please note that your final document will be submitted to our research office. You are requested to provide a signed list of data collectors, if applicable.

Sincerely,

Dr. NGARAMBE Christian
Ag. Director General of CHUB
Cc:

- Head of Clinical Education and Research Division
- Head of Clinical Services Division
- Director of Medical Services
- Director of DTS
- Director of Nursing Midwives

P.O Box: 254 Butare | Email: info@chub.rw | Hotline: 2030

3. RMH

Rwanda Defence Force
Military Health Service
RMRTH

REF: 280 /RMRTH/COMDT/2025 02 June 2025

Mutesi Mukinisha
University of Global Health Equity
Tel: +250 783 285 359
Email: mutesi.mukinisha@student.ughe.org

RE: ETHICAL CLEARANCE

1. Reference is made to your letter dated 24 April 2025, requesting for approval of your research protocol titled **"Prevalence of Intestinal Stomas in Rwanda and the Experiences of Individuals living with them: A mixed methods study"**, We are pleased to inform you that your protocol is approved.

2. Please note that approval of this protocol is valid for **12 months** from the date of this notice.

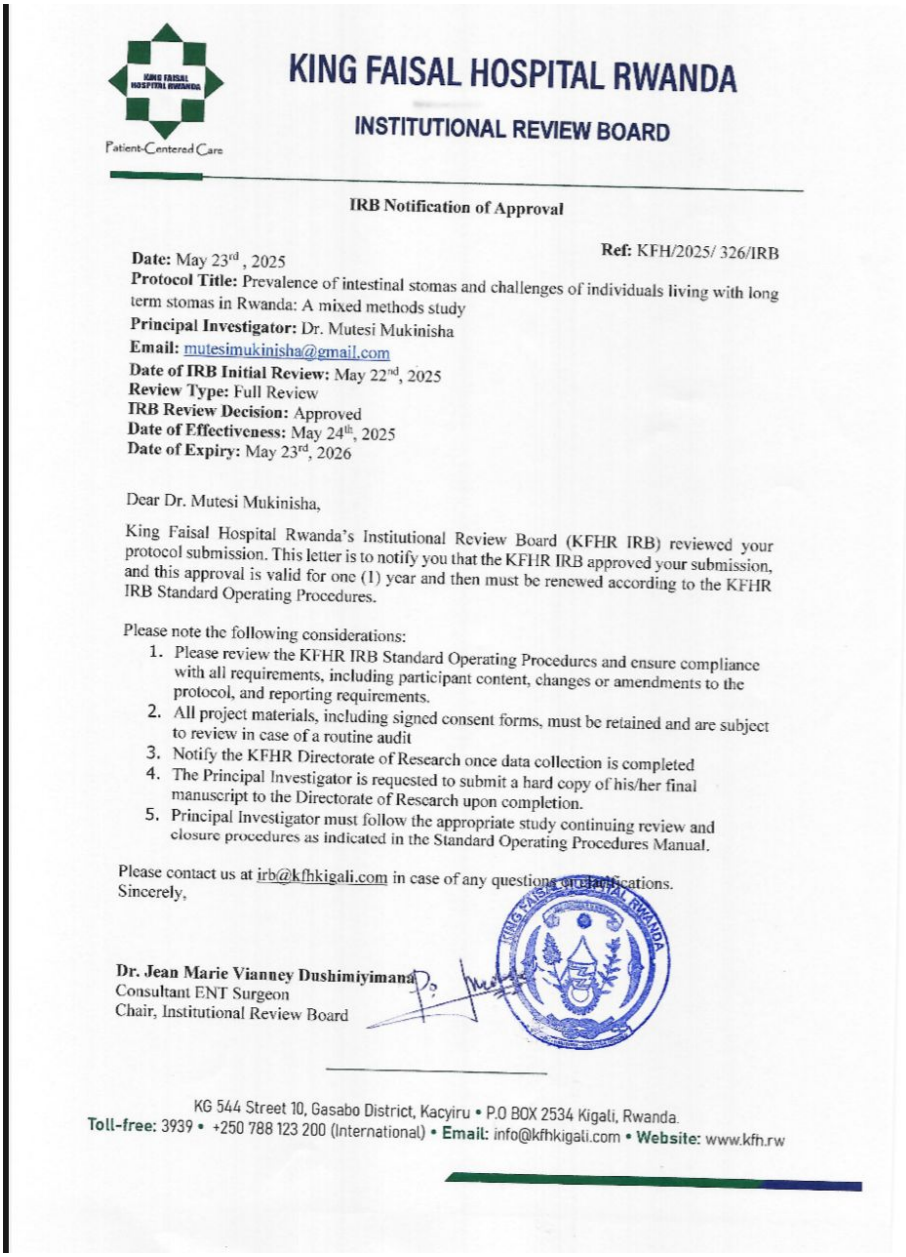
3. A continuing review application must be submitted to RMRTH/IRB in a timely fashion and before expiry of this approval.

4. The RMRTH/IRB must be notified at the closure of the study with a summary report.

Sincerely,

Dr E NGOGA
Brigadier General
Commandant

4. King Faisal Hospital



KING FAISAL HOSPITAL RWANDA

INSTITUTIONAL REVIEW BOARD

Patient-Centered Care

IRB Notification of Approval

Ref: KFH/2025/ 326/IRB

Date: May 23rd , 2025
Protocol Title: Prevalence of intestinal stomas and challenges of individuals living with long term stomas in Rwanda: A mixed methods study
Principal Investigator: Dr. Mutesi Mukinisha
Email: mutesimukinisha@gmail.com
Date of IRB Initial Review: May 22nd, 2025
Review Type: Full Review
IRB Review Decision: Approved
Date of Effectiveness: May 24th, 2025
Date of Expiry: May 23rd, 2026

Dear Dr. Mutesi Mukinisha,

King Faisal Hospital Rwanda's Institutional Review Board (KFHR IRB) reviewed your protocol submission. This letter is to notify you that the KFHR IRB approved your submission, and this approval is valid for one (1) year and then must be renewed according to the KFHR IRB Standard Operating Procedures.

Please note the following considerations:

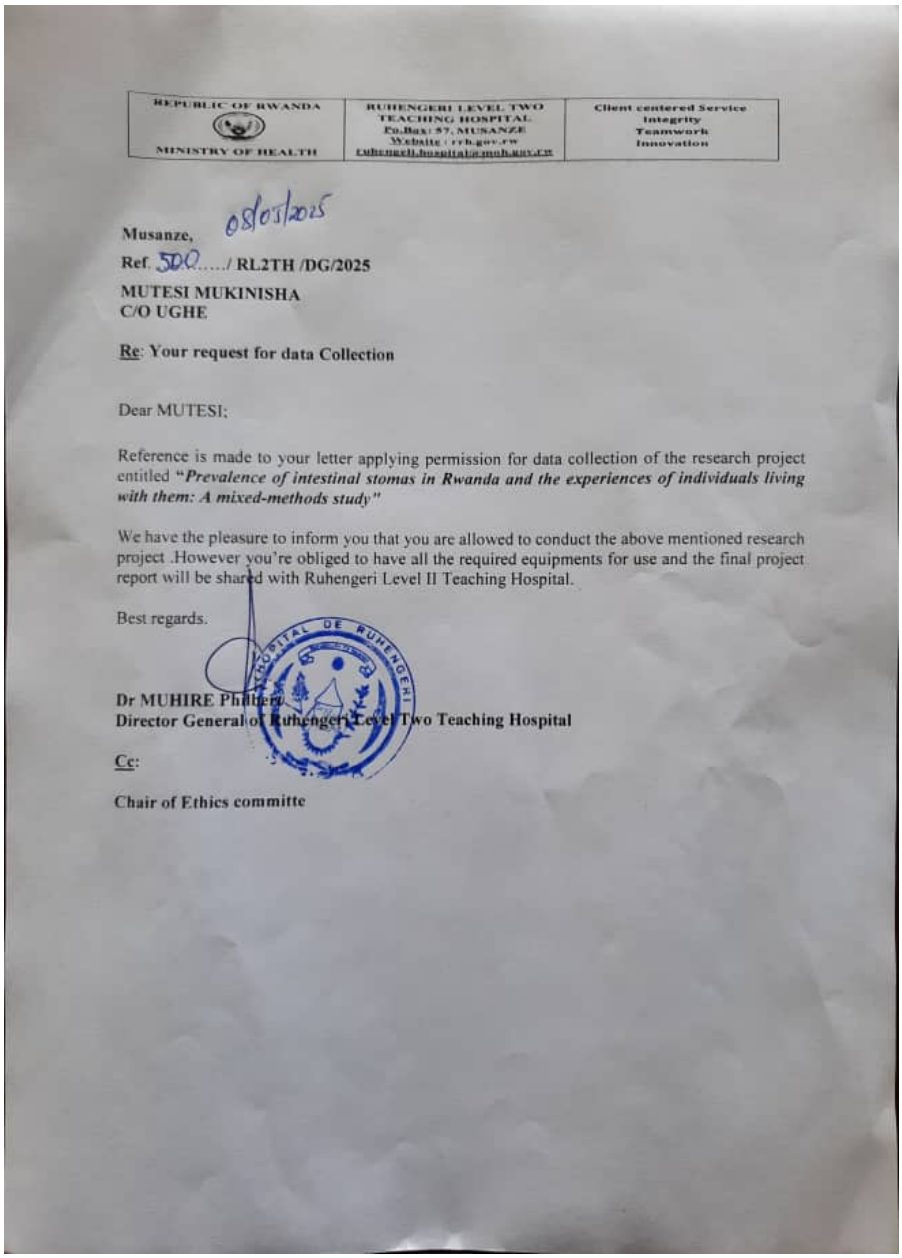
1. Please review the KFHR IRB Standard Operating Procedures and ensure compliance with all requirements, including participant content, changes or amendments to the protocol, and reporting requirements.
2. All project materials, including signed consent forms, must be retained and are subject to review in case of a routine audit
3. Notify the KFHR Directorate of Research once data collection is completed
4. The Principal Investigator is requested to submit a hard copy of his/her final manuscript to the Directorate of Research upon completion.
5. Principal Investigator must follow the appropriate study continuing review and closure procedures as indicated in the Standard Operating Procedures Manual.

Please contact us at irb@kfhkigali.com in case of any questions or clarifications.
Sincerely,

Dr. Jean Marie Vianney Dushimiyimana
Consultant ENT Surgeon
Chair, Institutional Review Board

KG 544 Street 10, Gasabo District, Kacyiru • P.O BOX 2534 Kigali, Rwanda.
Toll-free: 3939 • +250 788 123 200 (International) • **Email:** info@kfhkigali.com • **Website:** www.kfh.rw

5. Ruhengeri Level 2 Teaching Hospital



REPUBLIC OF RWANDA
MINISTRY OF HEALTH

RUHENGERI LEVEL TWO TEACHING HOSPITAL
Po.Box: 57, MUSANZE
Website : rrh.gov.rw
ruhengeri.hospital@moh.gov.rw

Client centered Service
Integrity
Teamwork
Innovation

Musanze, 08/05/2025

Ref. 500...../ RL2TH /DG/2025

MUTESI MUKINISHA
C/O UGHE

Re: Your request for data Collection

Dear MUTESI;

Reference is made to your letter applying permission for data collection of the research project entitled **"*Prevalence of intestinal stomas in Rwanda and the experiences of individuals living with them: A mixed-methods study*"**

We have the pleasure to inform you that you are allowed to conduct the above mentioned research project .However you're obliged to have all the required equipments for use and the final project report will be shared with Ruhengeri Level II Teaching Hospital.

Best regards.

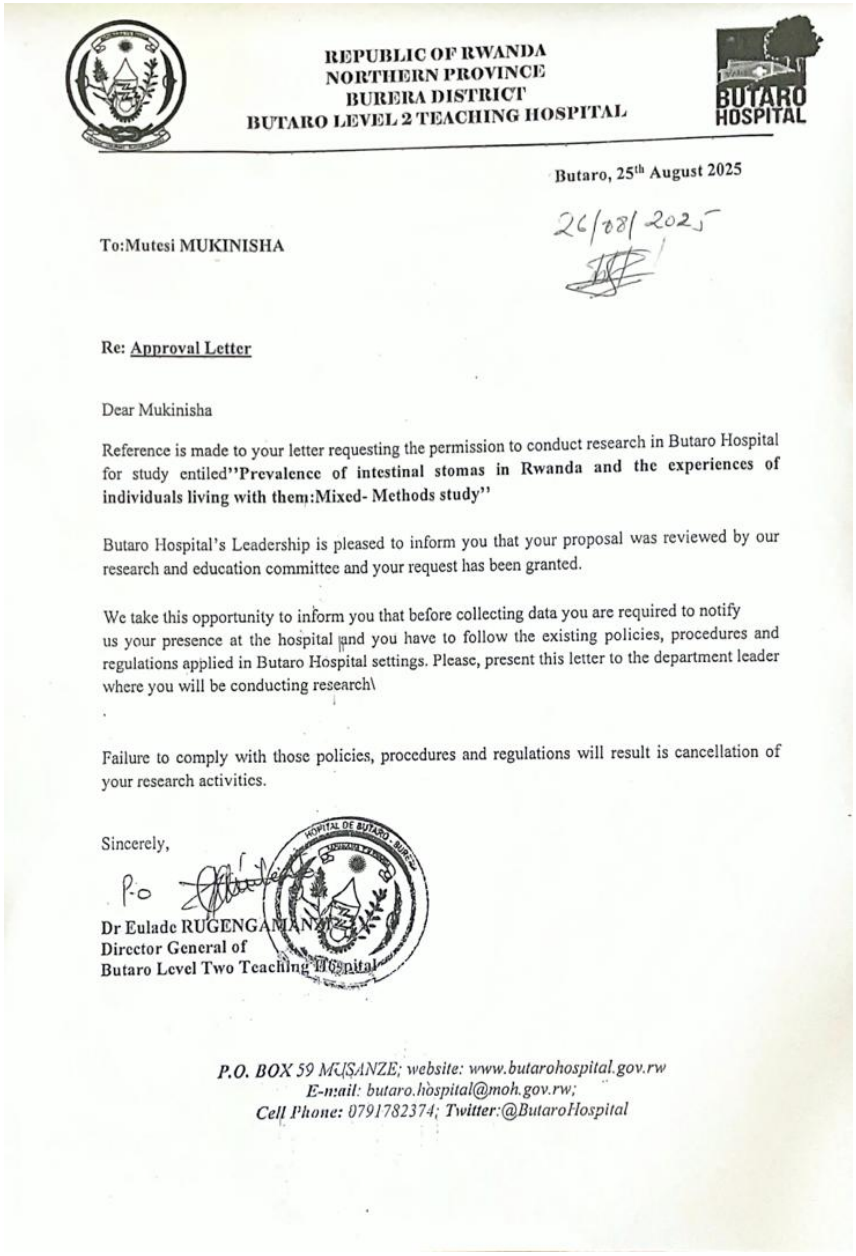
HOPITAL DE RUHENGERI

Dr MUHIRE Philbert
Director General of Ruhengeri Level Two Teaching Hospital

Cc:

Chair of Ethics committe

6. Butaro Level Two Teaching Hospital



REPUBLIC OF RWANDA
NORTHERN PROVINCE
BURERA DISTRICT
BUTARO LEVEL 2 TEACHING HOSPITAL

BUTARO HOSPITAL

Butaro, 25th August 2025

26/08/2025

To:Mutesi MUKINISHA

Re: Approval Letter

Dear Mukinisha

Reference is made to your letter requesting the permission to conduct research in Butaro Hospital for study entiled''**Prevalence of intestinal stomas in Rwanda and the experiences of individuals living with them:Mixed- Methods study**''

Butaro Hospital's Leadership is pleased to inform you that your proposal was reviewed by our research and education committee and your request has been granted.

We take this opportunity to inform you that before collecting data you are required to notify us your presence at the hospital and you have to follow the existing policies, procedures and regulations applied in Butaro Hospital settings. Please, present this letter to the department leader where you will be conducting research\

Failure to comply with those policies, procedures and regulations will result is cancellation of your research activities.

Sincerely,

P.o

Dr Eulade RUGENGAMANZI
Director General of
Butaro Level Two Teaching Hospital

HOSPITAL DE BUTARO - BURERA

P.O. BOX 59 MUSANZE; website: www.butarohospital.gov.rw
E-mail: butaro.hospital@moh.gov.rw;
Cell Phone: 0791782374; Twitter:@ButaroHospital

7. Rwamagana Level Two Teaching Hospital

REPUBLIC OF RWANDA MINISTRY OF HEALTH	RWAMAGANA LEVEL II TEACHING HOSPITAL NR3, KIGALI-KAYONZA RD RWAMAGANA DISTRICT EASTERN PROVINCE PO BOX 06 RWAMAGANA PHONE NUMBER: +250783287108 E-mail: rwamagana.hospital@moh.gov.rw

Rwamagana, 8./.6.../ 2025
N° 14 /176 / Hop/RGNA/2025

To: Mutesi Mukinisha
MSc Candidate in Global Health Delivery
University of Global Health Equity (UGHE)

RE: Authorization to conduct Research at Rwamagana Level II Teaching Hospital.

Dear Mutesi,

Reference is made on your email of 07th May 2025, requesting to conduct Research at Rwamagana Level II Teaching Hospital, Study entitled **"Prevalence of Intestinal Stomas in Rwanda and The Experiences of Individuals Living with Tem: A Mixed -Methods Study";**

Reference is made also to UGHE Institutional review Board letter N° UGHE-IRB/2025/363 of 01stApril 2025 and Ministry of Health Authorization letter to conduct research N° 20/1064/DPMEHF/2025 of 14th April 2025 ;

Based on Ethics committee requirements and Research committee recommendations; we are glad to inform you that the permission to conduct academic research, is given to you.

Therefore, you are requested to inform to Rwamagana Level II Teaching Hospital Ethics Committee all modifications on your Research protocol and you will submit a copy of your research findings to Hospital Research committee.

Best regards.

Dr Placide NSHIZIRUNGU
Director General of Rwamagana Hospital

8. Kabgayi Level Two Teaching Hospital

KABGAYI DIOCESE

MINISTRY OF HEALTH
KABGAYI LEVEL 2 TEACHING HOSPITAL
B.P: 66 GITARAMA-RWANDA
E-mail: info@kabgayihospital.rw
: kabgayi.hospital@moh.gov.rw
: kabgayihospital1@gmail.com

Kabgayi on 26th August 2025

N°.546./HOP/MJB/tj

To: MUTESI MUKINISHA

Tel: +250783285359

E-mail: mutesi.mukinisha@student.ughe.org

Subject: Approval to Conduct Data Collection

Dear MUKINISHA,

Following your request for institutional approval to conduct the research study titled "*"Prevalence of Intestinal Stomas in Rwanda and the Experiences of Individuals Living with Them: A Mixed-Methods Study.";*

The Ethics Committee of Kabgayi Level Two Teaching Hospital has reviewed your request to collect data for your research project. We are pleased to inform you that, your request has been approved. You are hereby granted permission to proceed with data collection within the hospital under the following conditions:

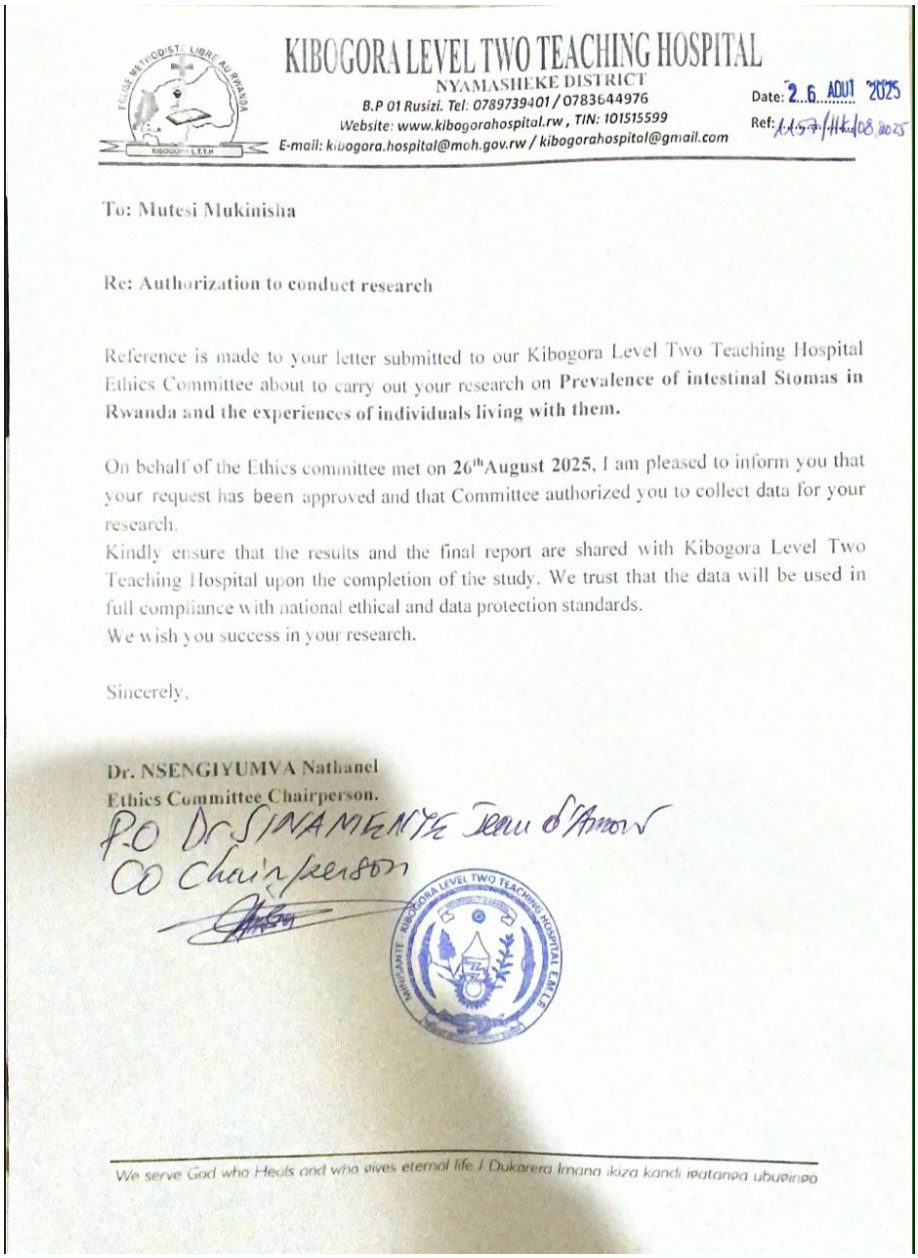
1. **Collaboration with the Research and Grant Management Officer (RGMO):** You are required to work closely with the RGMO at KL2TH throughout your research period. This ensures institutional alignment, support, and adherence to hospital research guidelines.
2. **Submission of Final Report:** Upon completion of your study, you are expected to submit a **digital and printed copy** of your final research report to the RGMO.

Sincerely,

Dr. MUVUNYI Jean Baptiste

Director General of Kabgayi Level Two Teaching Hospital

9. Kibogora Level Two Teaching Hospital



KIBOGORA LEVEL TWO TEACHING HOSPITAL
NYAMASHEKE DISTRICT
B.P 01 Rusizi. Tel: 0789739401 / 0783644976
Website: www.kibogorahospital.rw , TIN: 101515599
E-mail: kibogora.hospital@moh.gov.rw / kibogorahospital@gmail.com

Date: 26 AOUT 2025
Ref: 1457/HK/08.2025

To: Mutesi Mukinisha

Re: Authorization to conduct research

Reference is made to your letter submitted to our Kibogora Level Two Teaching Hospital Ethics Committee about to carry out your research on **Prevalence of intestinal Stomas in Rwanda and the experiences of individuals living with them.**

On behalf of the Ethics committee met on **26th August 2025**, I am pleased to inform you that your request has been approved and that Committee authorized you to collect data for your research.
Kindly ensure that the results and the final report are shared with Kibogora Level Two Teaching Hospital upon the completion of the study. We trust that the data will be used in full compliance with national ethical and data protection standards.
We wish you success in your research.

Sincerely,

Dr. NSENGIYUMVA Nathanel
Ethics Committee Chairperson.
P.O Dr SINAMENYE Jean d'Amour
CO Chairperson

We serve God who Heals and who gives eternal life / Dukorera Imana ikiza kandi iratanga ubuzima