

Master Thesis

**Stakeholders' perceptions and attitudes towards cost recovery at the
MRC/UVRI and LSHTM biobank in Uganda**

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For the academic degree of

Master of Science Biobanking

(MSc)

at the

Medical University of Graz

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Submitted 2025

Place, Date: Uganda, 10/07/2025

Statutory Declaration

I declare on my honour that I have written this dissertation independently and without assistance, that no sources other than those cited were used and that the sources used verbatim or in substance have been marked as such.

Graz 10/07/2025

Signature Esther Nabanoba

Acknowledgements

All activities and tasks towards this work would not have been successful without the gift of life that is granted by the Almighty God. I acknowledge His presence in my life.

My sincere and heartfelt appreciation to Prof Berthold Huppertz, for all the guidance rendered throughout this research journey. Ms Gabriele Hartl for the continuous support during the course duration and not forgetting Prof Karina for the motivation, support and encouragement to pursue this biobanking course, I do appreciate you all.

Abstract

Biobanks are vital infrastructures that support biomedical research by collecting, storing, and distributing biospecimens and associated data. Despite their importance, biobanks particularly in low- and middle-income countries face persistent challenges related to financial sustainability. One strategy increasingly recommended to address this issue is cost recovery: the implementation of mechanisms through which biobanks can recoup operational costs from users of their services. However, successful implementation of such models depends heavily on stakeholder understanding, acceptance, and engagement. This study explores stakeholder perceptions and attitudes towards cost recovery at the MRC/UVRI and London School of Hygiene and Tropical Medicine Biobank in Uganda.

Using a cross-sectional survey design, data were collected from 19 stakeholders drawn from five categories: biobank staff, researchers, administrative personnel, laboratory technologists, and suppliers. The structured questionnaire captured both quantitative and qualitative data, covering key themes such as awareness and understanding of cost recovery, perceived importance and necessity, perceived operational impacts, willingness to pay, implementation challenges, and stakeholder recommendations for improvement. Descriptive statistics were used to analyse frequency distributions, while thematic analysis was conducted on open-ended responses.

The results showed broad support for cost recovery, with most stakeholders recognizing it as critical for the biobank's long-term sustainability. However, the study also uncovered significant variations in levels of understanding. While biobank staff and laboratory technologists exhibited strong familiarity with cost recovery implementation, administrative personnel and external collaborators demonstrated lower levels of awareness, suggesting communication gaps and limited stakeholder engagement. Many participants advocated for a balanced approach—supporting cost recovery while emphasizing the importance of maintaining accessibility, especially for early-career researchers and institutions with limited funding.

Major challenges identified included lack of stakeholder sensitization, affordability concerns, unclear policy frameworks, and limited funding from institutional or

external sources. Ethical concerns and stakeholder resistance were also reported. Recommendations provided by respondents included increasing stakeholder awareness through training and sensitization, offering subsidies for specific user groups, enhancing transparency in pricing, and benchmarking with other institutions implementing similar models.

The findings of this study reinforce existing literature on the complexity of introducing cost recovery systems in research infrastructures. They highlight the need for participatory planning, continuous communication, and equitable implementation strategies. These insights are critical for informing the development of sustainable, inclusive, and ethically sound cost recovery models in biobank settings across sub-Saharan Africa and other resource-constrained contexts.

Zusammenfassung

Biobanken sind essenzielle Infrastrukturen zur Unterstützung der biomedizinischen Forschung, da sie biologische Proben und zugehörige Daten sammeln, lagern und bereitstellen. Trotz ihrer Bedeutung stehen Biobanken – insbesondere in Ländern mit niedrigem und mittlerem Einkommen – vor anhaltenden Herausforderungen hinsichtlich der finanziellen Nachhaltigkeit. Eine zunehmend empfohlene Strategie zur Bewältigung dieses Problems ist das Kostenrückgewinnungsmodell, bei dem Biobanken ihre Betriebskosten durch Gebühren von Nutzern ihrer Dienste teilweise decken. Der Erfolg solcher Modelle hängt jedoch stark vom Verständnis, der Akzeptanz und der Beteiligung der Interessengruppen ab. Diese Studie untersucht die Wahrnehmungen und Einstellungen der Stakeholder zur Kostenrückgewinnung an der MRC/UVRI and London School of Hygiene and Tropical Medicine Biobank in Uganda.

Mittels eines querschnittlichen Umfragedesigns wurden Daten von 19 Stakeholdern aus fünf Kategorien erhoben: Biobank-Mitarbeitende, Forschende, Verwaltungspersonal, Labortechniker:innen und Zulieferer. Der strukturierte Fragebogen erfasste sowohl quantitative als auch qualitative Daten und behandelte zentrale Themen wie das Bewusstsein und Verständnis für die Kostenrückgewinnung, deren wahrgenommene Bedeutung und Notwendigkeit, Auswirkungen auf den

Betrieb, Zahlungsbereitschaft, Umsetzungsherausforderungen und Empfehlungen der Stakeholder. Die Auswertung erfolgte durch deskriptive Statistik für die quantitativen Daten und thematische Analyse für die offenen Antworten.

Die Ergebnisse zeigten eine breite Unterstützung für die Kostenrückgewinnung, wobei die meisten Stakeholder diese als entscheidend für die langfristige Nachhaltigkeit der Biobank ansahen. Gleichzeitig offenbarte die Studie jedoch deutliche Unterschiede im Verständnisniveau. Während Biobank-Mitarbeitende und Labortechniker:innen eine hohe Vertrautheit mit der Umsetzung zeigten, wiesen Verwaltungsangestellte und externe Partner ein geringeres Bewusstsein auf – was auf Kommunikationsdefizite und mangelnde Einbindung hinweist. Viele Befragte befürworteten einen ausgewogenen Ansatz, bei dem Kostenrückgewinnung unterstützt wird, ohne die Zugänglichkeit – insbesondere für Nachwuchsforschende und weniger finanzstarke Einrichtungen – zu gefährden.

Als zentrale Herausforderungen wurden mangelnde Sensibilisierung der Stakeholder, Bedenken hinsichtlich der Bezahlbarkeit, unklare politische Rahmenbedingungen sowie begrenzte Finanzierungsquellen genannt. Auch ethische Bedenken und Widerstand innerhalb der Stakeholder-Gruppen wurden thematisiert. Die Empfehlungen umfassten unter anderem gezielte Schulungen und Sensibilisierungsmaßnahmen, Subventionen für bestimmte Nutzergruppen, transparente Preisgestaltung sowie Vergleiche mit ähnlichen Einrichtungen.

Die Ergebnisse dieser Studie bestätigen die Komplexität der Einführung von Kostenrückgewinnungsmodellen in Forschungsinfrastrukturen. Sie unterstreichen die Notwendigkeit partizipativer Planung, kontinuierlicher Kommunikation und gerechter Umsetzungsstrategien. Diese Erkenntnisse sind entscheidend für die Entwicklung nachhaltiger, inklusiver und ethisch vertretbarer Modelle der Kostenrückgewinnung im Kontext von Biobanken in Subsahara-Afrika und anderen ressourcenbegrenzten Regionen.

Abbreviations

LSHTM	London School of Hygiene & Tropical Medicine
MRC	Medical Research Council
UVRI	Uganda Virus Research Institute
OECD	Organisation for Economic Co-operation and Development
LMIC	Low and Middle Income Country

List of tables

Table 1.....	16
Table 2.....	17
Table 3.....	17
Table 4.....	18
Table 5.....	19
Table 6.....	20
Table 7.....	21
Table 8.....	21
Table 9.....	23
Table 10.....	24
Table 11.....	25
Table 12.....	25
Table 13.....	26
Table 14.....	27
Table 15.....	28
Table 16.....	29
Table 17.....	30
Table 18.....	31
Table 19.....	32
Table 20.....	32
Table 21.....	33
Table 22.....	34
Table 23.....	36

Table of contents

Statutory Declaration	ii
Acknowledgements.....	iii
Abstract.....	iv
Zusammenfassung.....	v
Abbreviations.....	vii
1.0 INTRODUCTION	1
1.1 Problem statement.....	3
1.2 Purpose of The Study	4
1.3 Objectives.....	5
1.4 Research Questions	5
2.0 LITERATURE REVIEW	6
3.0 METHODOLOGY	8
3.1 Introduction.....	8
3.2 Study design.....	8
3.3 Study area and population.....	9
3.4 Sample size.	10
3.5 Data collection	10
3.6 Validity and reliability of the tool.....	11
3.7 Data analysis	12
3.8 Funding	13
3.9 Ethical consideration.....	13
4.0 RESULTS	14
5.0 DISCUSSION.....	38
5.1 Conclusion.....	53
References.....	54
ANNEX.....	61

CHAPTER ONE.

1.0 INTRODUCTION

Biobanking

Biobanking involves the collection of samples of plants, animals, the environment, and humans. Biobanks process, store and distribute biospecimens and associated data for use in research and clinical care. There are several types of human biobanks: disease-centric, population based, genetic or DNA/RNA, project-driven, tissues versus multiple specimen type, commercial and virtual biobanks (1). Biobanking according to Ouangraoua (2) is a very important concept in terms of global health security systems and preventing the next disease outbreak, yet, it is often overlooked in most health care systems, since response against diseases is their major focus.

Ouangraoua (2) suggests that a biobank or collection of biological samples should guarantee biological specimens originating from humans, plants, animals, and all other elements of nature to remain in optimal conditions for use by various stakeholders to enhance research and knowledge worldwide. This enables the discoveries in medicine, vaccines, and diagnostic tests to enhance epidemiological surveillance and genomic research, including the pursuit of treatments for multiple cancers. For example, tumor samples donated by clients with cancer of the breast have been used to identify therapeutic targets and help predict, which subgroup of individuals would or would not benefit from a specific treatment; hence, providing information that is important for formulating a treatment strategy.

Biobanking at the global level

Chen and Pang (3) suggest that even though genetics and genomics have contributed to better understanding of causes and mechanisms of human diseases, some researchers are still concerned that genetic research has mainly focused on the health needs of high-income countries, therefore growing health inequity between people in low and high-income nations. This means new knowledge and technologies from epidemiological and genetic research is more beneficial for high-income countries than low- and middle-income countries. This is partly due to the lack of biobanks and large cohort studies in low and middle-income countries.

Biobanking itself may be viewed as an ambitious task, given that researchers have to grapple with an array of basic ethical, legal, and social issues, including informed consent, benefit sharing, confidentiality, ownership, commercialization, and public participation. Transnational biobanking is even more challenging because sample sharing and interoperability of data need to take place within an ethically and legally mutually applicable frame. Compared with the debate about ethical, legal, and social issues of biobanks in high-income countries, researchers in low- and middle-income countries are less experienced in coping with these issues. Fear of exploitation i.e. being subject to an unfair distribution of risks and benefits makes many countries from low- to middle-income economies, hesitate when their human biological samples and associated data are accessed and used by foreign researchers.

The increase in biobank numbers in low and middle-income countries has resulted in ethical issues, cross-border issues, and benefit sharing issues not seen in other areas of human research due to local culture and religious beliefs and due to poor awareness of the concept of ethics as perceived by developed countries (3). Low and middle-income countries have weak research capacities and governance mechanisms for biobanks. Nevertheless, developing a feasible and reasonable governance framework at the global level is certainly relevant to ensure benefit sharing in biobank collaboration.

Biobanking in Uganda

According to Nsubuga *et al.* (4), Africans have the most genetic diversity, yet little is known about how genes and the environment affect disease in Africa. Biorepositories among other approaches have been established as an avenue to address this issue. The H3Africa Program, through NIH funding, established biorepositories in Uganda, South Africa, and Nigeria from the years 2012 to 2013.

In 2016, the National Biorepository owned by the government of Uganda under the custodianship of Central Public Health Laboratories (CPHL) suggested a setup of a biorepository for appropriate storage of human biological materials for future research purposes in addition to research collaborations both locally and internationally. However, there is still no evidence of CPHL mapping existing biobanks in Uganda (5).

Many of the biobanks in Uganda are institution based. Establishment, regulation, accreditation and management of biobanks in Uganda is through the Uganda National Council for science and Technology (UNCST). This body provides the guidelines and policies that are followed with respect for research participants, protection from risks and engagement of the different stakeholders. UNCST also recently published guidelines on biobanking in Uganda (6).

Established at the request of the Ugandan Government in 1988, to the United Kingdom Government, the Medical Research Council/Uganda Virus Research Institute (MRC/UVRI) Uganda Research unit based in Entebbe is internationally recognized for its research on HIV and related diseases, which has helped understand and control the HIV pandemic in Uganda and globally. In 2017, the unit widened their research to include non-communicable diseases and other emerging health issues in Africa before creating a partnership with the London School of Hygiene & Tropical Medicine (LSHTM) on 1st February 2018 and rebranding to the MRC/UVRI and LSHTM Uganda Research unit. The unit hosts its central biobank in Entebbe.

1.1 PROBLEM STATEMENT

According to a study by Doucet *et al.* (7), biobanks require additional funding from governmental institutions and other stakeholders besides the funds they generate from biobank services. Sustainability in biobanking can be measured through financial, operational and social aspects. Even though focus has been on the financial component, it is important to recognize the role of the operational and social aspects and their contributions towards the sustainability of biobanks (8).

The cost of running a biobank is higher than what is perceived. For instance, staff costs, costs required to acquire, store and dispose of the specimens. There are also costs associated with the purchase and maintenance of software and hardware. Additionally, there are costs that come with running freezers used by biobanks such as electricity, monitoring, repairs and even replacements where necessary. These costs vary depending on how long the biobank has been operating, the quantity of specimen collected and their purpose (9).

According to Odeh *et al.* (10), the quality of specimens expected in biobanks is now high; this has increased many challenges economically among other ways. For

instance, the challenge in funds for start-up operations, maintenance, and growth. Secondly, biobanks face challenges in financing execution and appraising of best practices. Additionally, biobanks have an economic challenge in managing their inventory, where underutilized inventory costs can be reduced, and there is a balance between operational effectiveness and demonstrating return on investment.

Biobanks are also challenged by the overall determination of the total costs of the biobanking operation, costs allocated to their specimen, and justifiable cost recovery user fees that reflect the market and true cost of banking and storing individual samples. Therefore, one of the most frequent operational challenges, which thousands of biobanks face worldwide is the implementation of cost recovery-based business models.

Moreover, Singh *et al.* (11) observed that most investigations into the ethical, legal, and social implications of biobanking have focused on issues related to consent, storage, and sharing of samples, participant privacy, return of research results, benefit sharing, custodianship, governance, commercialization, and regulatory issues. A few investigations have examined how participants' and communities' beliefs, customs, and cultural and religious practices fit within existing biobanking research efforts. Community consultations have been generally reported to be very poor in Africa, which contributes to the public distrust of the research into biobanking.

However, with all the research on perceptions, knowledge and sustainability in biobanking, there is need to explore the perceptions and attitudes of the different stakeholders on cost recovery models in biobanks. The aim of this study is to assess the perceptions and attitudes of stakeholders towards the cost recovery model being implemented at the MRC/UVRI and LSHTM biobank. The information obtained from this study will inform management on strategies that are needed to ensure that the model is being acceptable and well adopted.

1.2 PURPOSE OF THE STUDY

This study aims to comprehensively assess stakeholders' perceptions and attitudes towards cost recovery at the Medical Research Council/ Uganda Virus Research Institute (MRC/UVRI) and London School of Hygiene and Tropical Medicine (LSHTM) biobank in Uganda. For this study, the stakeholders include researchers,

biobank staff, consumable suppliers, regulatory officers, compliance officers, quality managers, data managers and researchers. The study will also ascertain the level of knowledge of stakeholders towards cost recovery at the MRC/UVRI and LSHTM biobank in Uganda.

1.3 OBJECTIVES

To assess the level of knowledge of the stakeholders about cost recovery at the MRC/UVRI and LSHTM biobank in Uganda.

To assess the perceptions and attitudes of stakeholders towards cost recovery at the MRC/UVRI and LSHTM biobank in Uganda.

1.4 RESEARCH QUESTIONS

What is the level of knowledge of biobank staff, consumable suppliers and researchers about cost recovery at the MRC/UVRI and LSHTM biobank in Uganda?

What are the perceptions and attitudes of biobank staff, consumable suppliers and researchers towards cost recovery at the MRC/UVRI and LSHTM biobank in Uganda?

CHAPTER TWO

2.0 LITERATURE REVIEW

A biobank/biorepository is useful for prospectively collecting, storing, and disseminating specimens and related data. Mega repositories containing population-wide data have been developed in many countries worldwide. These biobanks have been created to collect, characterize, and store phenotypic and genetic data on representative samples of their source populations. Virtual biobanks are created to aid investigators in identifying biospecimens for testing and data mining from a variety of biobanks at scattered locations (1).

Kamulegeya *et al.* (12) also referred to biobanking as an emerging, fast-growing area of science that involves collection, processing, and storage and the issuance of biospecimens with their respective policies and procedures. Biobanks also form part of a silent substructure in scientific research, industry, and conservation without which much of the current scientific activity would be impossible. Such biobanks will, among others, unlock disease etiology and translation with far-reaching improvements in public health.

According to Malm *et al.* (13), global access to the biobank samples with associated clinical data, along with standardization, facilitates the ability to serve patients at the global level. In 2019, scientists at the Broad Institute of MIT and Harvard, together with colleagues at the University of Michigan and researchers from around the world, founded the Global Biobank Meta-analysis Initiative (GBMI) in efforts to connect international biobanks. This will allow for larger, more powerful studies of genetic data with more genetic ancestries and hence increase the chances of finding new genetic variants linked to diseases (14).

Biobanks have been collecting biological specimens for decades, but these banks were established in a more systematic manner in the 1990s, and most of them are found in high-income countries. Today, Africa is home to a human population that is surpassed by Asia, along with exceptional biodiversity, yet it provides very little toward advancing the research for treatment solutions. In fact, the project on biodiversity biobanks in South Africa has more than half a million items across various biobanks in the country, but there are only a few country-based biobanks on the continent, and these altogether contribute a trivial 2% of data used in genome-wide studies (2).

Ouangraoua (2) suggests that central biobanks require overcoming financial, infrastructural, organizational, and documentation difficulties to be set up successfully. They are fundamental in most health care approaches and treatments. They help reduce behaviors that put one's health in danger, ensure universal access to medical coverage and health services, and support research and development of vaccines and medicines for improving the management of health risks. This shows how critical biobanks are in saving lives within global health systems.

CHAPTER THREE

3.0 METHODOLOGY

3.1 Introduction

This chapter outlined the research methodology that was employed to carry out the study on stakeholders' perceptions and attitudes towards cost recovery at the MRC/UVRI and LSHTM Biobank in Uganda. The methodology elaborated the study design, the study area, the study population, the sample size, the data collection tools used, as well as the procedures for data collection and analysis. It also addressed the validity and reliability of the tools used, funding and ethical considerations that were followed throughout the research process.

By providing a detailed description of the methods, this chapter aimed to ensure transparency and replicability, outlining how each aspect of the study was carefully designed to meet the research objectives. The methods chosen were intended to gather data that is both reliable and relevant, offering insights into the perceptions and attitudes of stakeholders involved in cost recovery at the Biobank. The overall goal was to ensure that the study findings were robust, credible and contribute meaningfully to the ongoing dialogue on cost recovery practices in Biobank research.

3.2 Study design

The study employed a cross-sectional study design to assess stakeholders' perceptions and attitudes towards cost recovery at the MRC/UVRI and LSHTM Biobank in Uganda. A cross-sectional design involves the collection of data at a single point in time, providing a brief overview of the variables of interest without the need for follow-up. This design is appropriate for descriptive studies aiming to examine the prevalence of certain attitudes, opinions, or practices within a defined population (15).

Given that the primary objective of this study was to explore and describe the current views of stakeholders regarding cost recovery, a cross-sectional approach offers an efficient and practical method for gathering relevant data. It allows for the collection of information from multiple stakeholder groups simultaneously, enabling comparisons and the identification of patterns or trends within the biobank context.

The study adopted a quantitative data collection approach to ensure the generation of measurable and analyzable data. Quantitative methods are well suited for studies seeking to quantify attitudes and perceptions, providing a structured framework for statistical analysis and generalization of findings.

Data was collected using a self-administered questionnaire, which was designed to gather standardized information from participants while minimizing interviewer bias. The use of a self-administered tool allowed respondents the flexibility to complete the questionnaire at their convenience, thereby improving response accuracy and ensuring privacy. This method was also practical given the professional nature of the target population, who may prefer minimal interruptions in their work schedules.

In summary, the cross-sectional design, coupled with quantitative data collection through a self-administered questionnaire, was deemed most appropriate for achieving the study's objectives in a timely and resource efficient manner. However, it is acknowledged that cross-sectional designs capture perceptions at a single point in time and do not account for changes in attitudes that may occur over time. This limitation was considered in the interpretation of the study findings.

3.3 Study area and population

The study was conducted at the Medical Research Council/ Uganda Virus Research Institute and London School of Hygiene and Tropical Medicine (MRC/UVRI and LSHTM) based in Entebbe, Uganda. The Biobank serves as a central facility for the collection, processing, storage and distribution of biological samples to support scientific research within Uganda and internationally. It plays a critical role in facilitating biomedical research by providing high quality biological samples and associated data with researchers, thereby contributing to advancements in public health and disease prevention.

The study population included biobank staff, data managers, quality managers, consumable suppliers and researchers from different sites that make up the unit as well as suppliers who provide the biobank with consumables, equipment and IT software. These stakeholders are directly involved in or interact with the Biobank's operations and are therefore well positioned to provide informed perspectives on issues related to cost recovery. Their insights are essential for understanding the

practical, operational and strategic considerations that influence the implementation of cost recovery mechanisms within the biobank setting.

3.4 Sample size.

The study included a sample of 80 stakeholders. This number was considered adequate to provide representative insights from the various stakeholder groups involved with the MRC/UVRI and LSHTM Biobank. The sample size was determined using the Krejcie and Morgan size determination table (16), which provides a guideline for selecting an appropriate sample size based on the population size to ensure representativeness and statistical validity. This method is widely used in social sciences research to determine sample sizes for surveys and questionnaires.

A purposive sampling technique was employed to select participants for the study. This non-probability sampling method was appropriate because the study targets specific categories of stakeholders who are directly involved with or have relevant interactions with the biobank's cost recovery processes. These include biobank staff, data managers, quality managers, researchers and suppliers. Stakeholders without active engagement with the biobank were excluded from the sample. Purposive sampling allows the researcher to intentionally select individuals who possess the knowledge and experience necessary to provide meaningful insights related to the study objectives.

The chosen sample size of 80 stakeholders and the purposive sampling technique are considered adequate for capturing diverse perspectives from key stakeholders while remaining feasible within the scope and resources of the study.

3.5 Data collection

Participants were identified through the biobank's internal stakeholder lists and relevant contacts. An invitation email containing structured, a self-administered survey link, an informed consent form and confidentiality agreement was sent to each participant via email. The questionnaire included a combination of multiple-choice questions, Likert scale items (rated from 1 = strongly disagree to 5 = strongly agree), and a section for demographic information to capture respondent's background characteristics.

Prior to participation, stakeholders were required to provide informed consent. A consent form was embedded at the beginning of the questionnaire, appearing first when participants accessed the survey link. Only after consenting were participants able to proceed to the questionnaire. Additionally, participants were required to sign a confidentiality agreement to ensure the privacy and protection of their responses.

The questionnaire was used to collect data and automatically populate it into an Excel spreadsheet upon submission. This approach ensured efficiency in data management, reduced manual data entry errors and facilitated subsequent data analysis. All collected data were securely stored and handled in accordance with ethical guidelines to maintain confidentiality and data integrity.

Data collection was conducted over a period of one month from 1st May to 30th May 2025 to allow participants sufficient time to respond. The survey link was shared with the identified stakeholders via email, accompanied by a brief explanation of the study's purpose and clear instructions on how to complete the questionnaire.

The survey was designed to allow participants to complete it at their convenience, with submissions being automatically recorded upon completion. The collected data was then reviewed for completeness and accuracy before the analysis.

To enhance participation, follow-up reminders were sent weekly to encourage participation and improve response rates. This ensured that potential respondents had multiple opportunities to participate in the study. Responses were monitored regularly to track participation progress and to identify any incomplete responses, encouraging them to complete the questionnaire. All collected data was securely stored and was accessible only to the researcher to maintain confidentiality and data integrity.

3.6 Validity and reliability of the tool

To ensure the validity and reliability of the data collection tool, practical steps were taken during its development. The questionnaire was designed based on the study objectives and guided by existing literature on Biobanking and cost recovery practices.

Face validity was established through feedback from peers and the academic supervisor, focusing on the clarity, relevance and appropriateness of the questions.

Minor adjustments were made based on this feedback to improve question wording and flow.

A pilot test was also conducted with a small number of respondents who were not part of the final study sample. This helped to identify any ambiguities and to check for consistency in understanding the questions. The feedback from the pilot test informed final revisions of the questionnaire to enhance its reliability. These steps provided the reasonable assurance that the tool was both valid and reliable for the purpose of this study.

3.7 Data analysis

The collected data was exported in Microsoft Excel format. Prior to analysis, the data set was reviewed to ensure completeness and accuracy and any duplicate or incomplete entries were excluded. Descriptive statistics were used to generate frequencies, means and standard deviations to summarize stakeholder demographics and assess general patterns in awareness and attitudes towards cost recovery.

To examine differences in perceptions among different stakeholder groups (researchers, administrators and funders), comparative statistical analyses were conducted. Depending on the distribution of the data, either one way Analysis of Variance (ANOVA) or the non-parametric Kruskal-Wallis tests were employed. These analyses helped identify whether statistically differences existed in the perceptions of cost recovery across the stakeholder categories.

Furthermore, Pearson's correlation analysis was used to explore relationships between participants' attitudes towards cost recovery and selected variables such as their professional roles, length of involvement with Biobank activities and their views on financial sustainability and equity. The aim of these tests was to determine whether stakeholders' positions or experiences influenced their perspectives on cost recovery mechanisms. All statistical analyses were performed using Microsoft Excel and SPSS (or another software if different). The significance level was set at $p < 0.05$ for all inferential tests.

To facilitate meaningful group comparisons, participant responses to the question "What is your role at the biobank or in relation to its operations?" were grouped into broader stakeholder categories. This was necessary because the original responses

varied widely, including titles such as “Biobank staff”, “Data Management”, “Quality Manager”, “Project leader” and others. Grouping them allowed for more robust statistical analysis using techniques such as the Kruskal-Wallis test.

The grouping was done as follows:

Biobank staff: Respondents who explicitly identified their role as “Biobank Staff”.

Administrative staff: This included roles such as “Data Management”, “Quality Manager” and “Administrative staff” due to their shared operational and support functions within the biobank infrastructure.

Researchers: Respondents who identified as “Researcher”, “Project leader” or who described activities such as aliquoting samples or accessing biobank materials for study were grouped under this category.

Laboratory technologists: those listed as “Laboratory technologist” were categorised separately due to their technical role in processing and handling biospecimens.

Suppliers: one respondent who described their role as “Equipment/consumables Supplier” was placed in a distinct supplier category, given their external but relevant engagement with the biobank.

These stakeholder categories were used in subsequent statistical analyses to explore whether perceptions and attitudes toward cost recovery varied significantly across professional roles.

3.8 Funding

This is a self-funded master’s project.

3.9 Ethical consideration

Ethical approval was sought from the Uganda Virus Research Institute (UVRI) Research and Ethics committee and approval from Uganda National Council for Science and Technology (UNCST). Additionally, participants were fully informed of the nature of the research, their role in the study and their rights as participants. Consent was obtained in writing and data were stored securely and confidentially.

CHAPTER FOUR

4.0 RESULTS

Descriptive statistics

A total of 19 participants took part in the survey, representing a range of stakeholder roles including biobank staff, administrative staff, researchers, laboratory technologists and one consumable supplier. There were 4 biobank staff, 5 administrative staff, 7 researchers, 2 laboratory technologists and 1 supplier. There was 1 data manager and 1 quality manager categorized as administrative staff. There was also a project leader included among the researchers.

Participants ranged from age 25 to 64 with most participants in the 25-34 age range. Overall, there were more female participants than male. 12 participants identified as female and 7 identified as male. The majority of participants were directly involved in biobank operations either through sample handling, data management or research related roles.

Perceptions of cost recovery

Overall, familiarity with the concept of cost recovery varied across respondents. While some participants indicated they were very familiar with cost recovery at the biobank, others reported limited or no familiarity at all. Most participants agreed that cost recovery is important for the sustainability of biobank operations. A significant number of respondents were also aware of the types of costs included in the biobank's cost recovery model, such as storage and maintenance of biological samples, data management, equipment and administrative overheads.

Observed trends

Despite the lack of statistical significance, descriptive analysis showed some variation. For instance, biobank staff had the highest average familiarity score (3.75), while the supplier had the lowest (1.00). Researchers and administrative staff also showed moderate familiarity with average scores of 2.71 and 2.20 respectively. This

may reflect the degree of involvement with the biobank's operational and financial systems.

“To what extent do you understand how cost recovery is implemented at the biobank?”

Participants were asked to indicate the extent to which they understood how cost recovery is implemented at the biobank. Responses were scored on a scale from 1 (not familiar at all) to 4 (very well). A Kruskal-Wallis H test was conducted to determine whether there were statistically significant differences in understanding across stakeholder groups.

The analysis revealed the following average ranks for each group:

Biobank staff: n =4, average rank = 15.75

Administrative staff: n =5, average rank =6.70

Researchers: n = 7, average rank = 10.43

Laboratory technologist: n = 2, average rank =9.25

Supplier: n =1, average rank =2

The Kruskal-Wallis test indicated that the differences in understanding among stakeholder categories were not statistically significant, $H(4) = 8.00, p > 0.05$.

This suggests that while there are observable differences in mean ranks, these differences are not strong enough to conclude that stakeholder category significantly affects understanding of how cost recovery is implemented at the biobank.

Table 1: Stakeholder understanding of cost recovery implementation.

Stakeholder category	N (Participant)	Average Rank
Biobank staff	4	15.75
Administrative staff	5	6.70
Researchers	7	10.43
Laboratory technologists	2	9.25
Supplier	1	2.00

“Do you know what services or activities at the biobank are subject to cost recovery?”

Respondents were asked whether they knew how cost recovery is implemented at the biobank. Out of the 19 total respondents: 9 participants (47.4%) responded yes, 7 participants (36.8%) selected not sure and 3 participants (15.8%) responded no. Among stakeholder categories all biobank staff (100%) indicated they knew how cost recovery is implemented; researchers were split with 3 (42.9%) saying yes and 4 (57.1%) indicating that they were not sure. Among administrative staff, 2 said yes, 2 were not sure and 1 responded no. Laboratory technologists showed lower certainty, with 1 saying no and 1 not sure. The sole supplier indicated they did not know how cost recovery is implemented.

Overall, familiarity with cost recovery implementation was highest among Biobank staff, while uncertainty was more prevalent among researchers, administrative staff and laboratory technologists.

To determine whether stakeholder category was associated with knowledge of services subject to cost recovery, a chi-square test of independence was conducted. The results indicated that there was no statistically significant association between stakeholder category and response (chi squared (8) =14.35, $p = 0.073$).

Although the result was not statistically significant at the 0.05 level, some patterns were observed. For example, all biobank staff reported knowing which services are

subject to cost recovery, while suppliers exclusively reported not knowing.

Researchers showed mixed awareness, with a notable number indicating uncertainty.

Table 2: Stakeholder knowledge of services or activities subject to cost recovery.

Stakeholder Category	No	Not sure	Yes	Total
Administrative staff	1	2	2	5
Biobank staff	0	0	4	4
Laboratory technologist	1	1	0	2
Researcher	0	4	3	7
Supplier	1	0	0	1
Total	3	7	9	19

To assess the chi-squared results further, the expected frequencies were calculated.

Table 3: Expected frequencies for knowledge of services by stakeholder category.

Stakeholder category	Yes	Not sure	No
Biobank staff	1.89	1.47	0.63
Administrative staff	2.37	1.84	0.79
Researchers	3.32	2.58	1.11
Laboratory technologists	0.95	0.74	0.32
Supplier	0.47	0.37	0.16

“Do you know what types of costs are included in the biobank’s cost recovery model?”

Participants were asked to indicate which types of costs they believed were included in the biobank’s cost recovery model. Responses were grouped by stakeholder category to show patterns of awareness across roles. As shown in the table below, the most commonly identified cost across all groups was storage and maintenance of biological samples. Biobank staff and researchers were generally more familiar with a broader range of cost types, while administrative staff and suppliers identified fewer categories.

Table 4: Perceptions of cost recovery types included in the Biobank’s cost recovery model by stakeholder category

Cost type	Biobank staff	Administrative staff	Researchers	Laboratory technologists	Suppliers	Total mentions
Storage and maintenance	4	5	7	2	1	19
Data management costs	2	3	4	1	1	11
Staff salaries	2	3	2	1	1	9
Equipment and laboratory expenses	2	4	4	1	1	12
Maintenance of biobank infrastructure	3	4	5	1	0	13
Access to	3	2	4	2	0	11

biobank services						
Administrative overhead	2	2	2	1	0	7
Regulatory compliances	1	3	4	1	0	9
Research support	1	2	3	1	0	7

The table shows that the majority of stakeholders across all categories identified storage and maintenance of biological samples as a key cost included in the cost recovery model. Researchers and biobank staff were more likely than administrative staff or suppliers to recognize a broader range of cost types, such as regulatory compliance and data management costs. Notably, awareness of administrative overhead and staff salaries was more limited among non-research roles.

These findings suggest that storage and maintenance, infrastructure and laboratory related costs were the most widely recognized components of the cost recovery model, particularly among staff closely involved with operational and research functions.

To complement this stakeholder level view, the overall frequencies and percentages were also computed across all 19 participants, regardless of category.

Table 5: Overall frequency and percentage of cost types identified by participants (n= 19)

Cost type	Frequency (n)	Percentage (%)
Storage and maintenance	18	94.7%
Data management	11	57.9%
Staff salaries	9	47.4%

Equipment and laboratory expenses	12	63.2%
Maintenance of biobank infrastructure	13	68.4%
Access to biobank services	11	57.9%
Administrative overhead	7	36.8%
Regulatory compliance and legal fees	9	47.4%
Research support	7	36.8%

As reflected in Table 5, storage and maintenance of biological samples was the most commonly identified cost (94.7%), followed by infrastructure maintenance (68.4%) and equipment related expenses (63.2%). These results confirm strong stakeholder awareness of operational expenses but also point to some gaps in recognition of more indirect costs such as administrative overhead and research support.

“Do you know what services or activities at the biobank are subject to cost recovery?”

A chi-square test of independence was performed to examine the relationship between stakeholder category and awareness of which services at the biobank are subject to cost recovery. The results showed no statistically significant association between stakeholder category and awareness (chi-squared symbol (8) = 14.35, p=0.073).

Table 6: Observed frequencies and expected counts.

Stakeholder category	Yes	No	Not sure	Total
Biobank staff	4	0	0	4

Administrative staff	2	1	2	5
Researcher	3	0	4	7
Laboratory technologist	0	1	1	2
Supplier	0	1	0	1
Total	9	3	7	19

Table 7: Presents the observed frequencies of awareness by stakeholders.

Stakeholder category	Yes	No	Not sure
Biobank staff	1.89	0.63	1.47
Administrative staff	2.37	0.79	1.84
Researcher	3.32	1.11	2.58
Laboratory technologist	0.95	0.32	0.74
Supplier	0.47	0.16	0.37

“Type of costs included in the Biobank’s cost recovery model”

Table 8: Perceptions of cost types included in the Biobank’s cost recovery model(n=19)

Cost type	Frequency (n)	Percentage (%)
Storage and maintenance	18	94.7

Data management costs	11	57.9
Staff salaries	9	47.4
Equipment and laboratory expenses	12	63.2
Maintenance of biobank infrastructure	13	68.4
Access to biobank services	11	57.9
Administrative overhead	7	36.8
Regulatory compliance and legal fees	9	47.4
Research support	7	36.8

Participants were asked to indicate which types of costs they believed were included in the biobank’s cost recovery model. As shown in the tables above, the most commonly identified cost was storage and maintenance of biological samples (94.7%), followed by maintenance of biobank infrastructure (68.4%) and equipment and laboratory expenses (63.2%). Other frequently mentioned costs included data management costs (57.9%) and access to biobank services (57.9%). Less frequently selected were staff salaries (47.4%), regulatory compliance and legal fees (47.4%), administrative overhead (36.8%) and research support (36.8%).

“Awareness of biobank services”

Participants were asked to indicate their level of awareness of fees charged for biobank services. Responses were disaggregated by stakeholder category, revealing substantial variation in awareness levels across roles.

Table 9: Awareness of biobank service fees by stakeholder category.

Stakeholder category	Not aware at all	Not sure	Somewhat aware	Very aware	Total
Biobank staff	0	1	0	3	4
Administrative staff	1	3	1	0	5
Laboratory technologist	1	0	1	0	2
Researcher	3	0	3	1	7
Supplier	1	0	0	0	1
Total	6	4	5	4	19

As shown in Table 9, biobank staff had the highest proportion of respondents who reported being very aware (3 out of 4), indicating strong internal knowledge of pricing. In contrast, administrative staff and researchers displayed lower levels of awareness, with most administrative staff either unsure or unaware. The supplier respondent and laboratory technologists also demonstrated low levels of awareness, with no participants from these groups selecting “very aware.”

A chi-square test was conducted to determine whether the differences in awareness levels were statistically significant across stakeholder groups. The test yielded the following result: $\chi^2 (12, N = 19) = 18.50, p = 0.10$. Since the p-value exceeds 0.05, the result is not statistically significant. This suggests that while differences in awareness are observable (e.g., greater awareness among biobank staff), they are not strong enough to suggest a consistent, meaningful pattern across stakeholder groups.

These findings highlight some disparities in knowledge of service fees, particularly among roles less directly involved in day-to-day biobank operations, and may point to areas where internal communication or outreach could be improved.

“What do you think is the most important factor when considering cost recovery for the biobank?”

Participants were asked to indicate what they believed to be the most important factor when considering cost recovery at the biobank. Their responses are summarized in Table 10.

Table 10: Most important factor when considering cost recovery at the biobank (n=18).

Factor	Frequency	Percentage (%)
Sustainability of Biobank	11	61.1%
Transparency in pricing	5	27.8%
Affordability	2	11.1%
Total	18	100%

As shown in table 10, when asked about the most important factor when considering cost recovery at the Biobank, the majority of participants (61.1%) identified the sustainability of the biobank as the key concern. Others emphasized the importance of transparency in pricing (27.8%) and affordability (11.1%). These results suggest that while stakeholders are concerned with fairness and accessibility, they strongly prioritize ensuring the long-term viability of the biobank.

Participants perceived cost ranges for sample storage and retrieval at the biobank.

Participants were asked to estimate the cost of 2 key biobank services: sample storage per year and sample retrieval. The results are shown on tables 11 and 12.

Table 11: Estimated annual cost per sample for storage (n= 19)

Estimated cost per year per sample	Frequency
£0.20- £0.99	3
£1.00- £1.50	3
£2.00- £2.50	3
£3.00- £3.50	6
Not sure	4
Total	19

For sample storage, the most frequently selected estimate was £3.00 - £3.50, chosen by 6 participants (31.6%). The remaining responses were evenly distributed among the lower cost ranges £0.20- £0.99, £1.00- £1.50 and £2.00- £2.50, chosen by 3 participants (15.8%). Four participants indicated they were unsure of the actual cost.

Table 12: Estimated cost per sample retrieval (n= 19)

Estimated cost per retrieval	Frequency
£0.02- £0.10	8
£1.00- £1.50	6
Not sure	5
Total	19

Regarding sample retrieval, the most common estimate was £0.02- £0.10 per sample, selected by 8 participants (42.1%), followed by £1.00- £1.50, selected by 6 participants (31.6%). Five participants (26.3%) indicated they were not sure of the retrieval cost. These findings suggest a general awareness of cost levels but also point to inconsistencies in stakeholder knowledge.

Perceptions of the need for cost recovery

Participants were asked to indicate the extent to which they perceived a need for cost recovery at the biobank. Their responses by stakeholder category are shown in Table 13 below.

Table 13: Perceptions of the need for cost recovery by stakeholder category (n=19).

Stakeholder category	Strongly agree	Agree	Neutral	Strongly disagree	Total
Biobank staff	4	0	0	0	4
Administrative staff	3	1	0	1	5
Researcher	4	2	1	0	7
Laboratory technologist	2	0	0	0	2
Supplier	1	0	0	0	1
Total	14	3	1	1	19

As shown in table 13 above, participants were asked how they perceived the need for cost recovery at the biobank. The majority of respondents (14 out of 19) across all stakeholder groups strongly agreed with the need for cost recovery. This included all biobank staff (4 out of 4), both laboratory technologists (2 out of 2) and the sole supplier. Among administrative staff, three strongly agreed, one agreed and one strongly disagreed. Researchers were more varied in their responses, with four strongly agreeing, two agreeing and one responding neutrally.

To determine whether the differences in perceived need for cost recovery were statistically significant across stakeholder categories, a chi-square test of

independence was performed. The test revealed no significant association between stakeholder category and perceived need for cost recovery, $\chi^2 (12) = 7.45, p= 0.827$. This suggests that stakeholders, regardless of their category, held broadly similar views on the importance of cost recovery at the biobank.

“Is cost recovery essential for the sustainability of the biobank?”

Participants were asked directly whether they believed cost recovery was essential for the sustainability of the biobank. Table 14 presents the responses.

Table 14: Stakeholders perceptions on the essential role of cost recovery for sustainability (n= 19)

Stakeholder category	Number of respondents	Response: yes
Biobank staff	4	4
Administrative staff	5	5
Researchers	7	7
Laboratory technologist	2	2
Suppliers	1	1
Total	19	19

All 19 respondents across the five stakeholder categories agreed that cost recovery is essential for the sustainability of the biobank. This unanimous agreement indicates a strong, shared understanding and endorsement of the cost recovery model as a necessary mechanism for ensuring the long-term viability and operational continuity of the biobank. Given the uniformity of responses, statistical testing was not required.

Cost comparison when selecting Biobanks

Participants were asked whether they had ever compared costs and selected the cheapest biobank when sourcing samples. Responses are shown in table 15.

Table 15: stakeholder responses to whether they compared costs and chose the cheapest biobank (n= 19)

Stakeholder category	Yes	No	Total
Biobank staff	2	2	4
Administrative staff	0	5	5
Researcher	0	7	7
Laboratory technologist	1	1	2
Supplier	0	1	1
Total	3	16	19

When asked whether they had ever compared costs and selected the cheapest biobank when sourcing samples, only 3 out of 19 participants (15.8%) responded “yes”. These included 2 biobank staff members and 1 laboratory staff technologist. The remaining 16 participants (84.2%) responded “No”, with no affirmative responses recorded from administrative staff, researchers or the supplier group.

Given the overwhelmingly negative responses across all stakeholder categories and the small number of “yes” answers, no statistical test was conducted for this question. However, the responses suggest that cost comparison is not a common practice among most stakeholders, especially researchers and administrative personnel.

Perceptions of differential cost recovery rates

Participants were also asked whether they believed there should be different cost recovery rates for academic scientists compared to industrial researchers. Table 16 summarizes their responses.

Table 16: perceptions on differential cost recovery rates by stakeholder category (n= 19)

Stakeholder category	Yes	No	Total
Biobank staff	3	1	4
Administrative staff	2	3	5
Researcher	7	0	7
Laboratory technologist	1	1	2
Supplier	0	1	1
Total	13	6	19

A majority of participants (13 out of 19; 68.4%) agreed that there should be different cost recovery rates for academic scientists versus industrial researchers. Notably, all 7 researchers who responded to this question supported differential rates, potentially reflecting their awareness of budgetary constraints within academic research. Among biobank staff, 3 out of 4 agreed, while administrative staff were more divided, with 3 opposing and 2 supporting the idea. Laboratory technologists were evenly split and the single supplier respondent did not support differential rates. These findings highlight varying perspectives across stakeholder groups, with researchers showing the strongest consensus in favor of tiered cost recovery.

Perceived impact of implementing cost recovery at the biobank

Participants were asked to identify the perceived impacts of implementing cost recovery at the Biobank. Multiple responses were allowed. The results are presented in table 17.

Table 17: Perceived impacts of cost recovery implementation (n= 19)

Impact option	Frequency (n)	Percentage (%)
Improved sustainability of biobank operations	17	89.5%
Greater access to biobank services	12	63.2%
Improved efficiency	12	63.2%
Innovation and expansion	7	36.8%
Increased research opportunities	6	31.6%
Optimal resource use	4	21.1%
Reduced access due to increased costs	2	10.5%

Note: Percentages are based on the total number of respondents (n=19), and since participants could select more than one option, the total exceeds 100%.

The majority of respondents (89.5%) believed that implementing cost recovery would lead to improved sustainability of the biobank. Improved efficiency and greater access to biobank services were each identified by 63.2% of participants.

Fewer participants mentioned innovation, increased research opportunities and optimal resource use. Notably only 2 respondents (10.5%) perceived reduced access as a potential consequence of implementing cost recovery.

Perceptions of willingness to pay for biobank services

Respondents were asked whether they believed biobank clients were willing to pay for services offered at the biobank. Their responses by stakeholder group are shown in table 18.

Table 18: Stakeholder perceptions of client willingness to pay for biobank services (n= 19)

Stakeholder Category	Yes	Unsure	Total
Biobank staff	3	1	4
Administrative staff	4	1	5
Researcher	4	3	7
Laboratory technologist	1	1	2
Supplier	0	1	1
Total	12	7	19

A majority of respondents (63.2%) believed clients are willing to pay, while 36.8% were unsure. Administrative staff showed the highest confidence (80% said “yes”), followed by biobank staff (75%). Researchers were more uncertain, with 42.9% unsure. Laboratory technologists were evenly split, and the single supplier expressed

Participants were asked whether they believed biobank clients are willing to pay for services.

Table 19: Percentage by stakeholder responses on client willingness to pay

Stakeholder category	Yes (%)	Unsure (%)
Biobank staff	75%	25%
Administrative staff	80%	20%
Researcher	57.1%	42.9%
Laboratory technologist	50%	50%
Supplier	0%	100%

These responses suggest general optimism among stakeholder groups, although uncertainty is more common among groups further from direct client interaction. uncertainty.

Perceived challenges of implementing cost recovery at the biobank

Table 20: Perceived challenges of implementing cost recovery at the biobank (n= 19)

Challenge	Frequency (N)	Percentage (%)
Limited understanding of cost recovery	14	73.7%
Lack of funding from stakeholders	13	68.4%
Affordability concerns for certain stakeholders	13	68.4%
Resistance from stakeholders	12	63.2%
Ethical concerns	3	15.8%
Total responses	65	

Note: Percentages are based on a total of 19 participants. Participants were allowed to select more than one challenge. As a result, the total percentages exceed 100%.

Participants identified several challenges to implementing cost recovery at the biobank listed in table 20 above. The most commonly cited concern was limited understanding of cost recovery mechanisms, selected by 14 out of 19 participants (73.7%). This was followed by lack of funding from stakeholders and affordability concerns, each cited by 13 participants (68.4%). Resistance from stakeholders was also prominent, mentioned by 12 participants (63.2%). Ethical concerns were least cited, selected by only 3 participants (15.8%).

Stakeholder perspectives on cost recovery prioritization

Table 21: stakeholder views on cost recovery prioritization (n= 19).

Stakeholder category	Prioritize cost recovery	A balance between the two	Total
Biobank staff	1	3	4
Administrative staff	2	3	5
Researcher	4	3	7
Laboratory technologist	1	1	2
Supplier	1	0	1
Total	9	10	19

When asked whether the biobank should prioritize cost recovery or focus on providing services at no cost to users, responses were nearly evenly split. Out of 19 participants, 9 (47.4%) believed the biobank should prioritize cost recovery, while 10 (52.6%) preferred a balanced approach.

Most biobank staff (3 out of 10) and a majority of administrative staff (3 out of 5) preferred balance. While researchers showed the strongest support for prioritizing cost recovery (4 out of 7), a notable portion still leaned toward a balanced model. These findings suggest that while financial sustainability is valued, many stakeholders also recognize the importance of maintaining accessibility to biobank services.

Thematic grouping of stakeholder recommendations

Table 22: Thematic grouping of stakeholder recommendations (n= 19)

Theme	Example responses	N
Stakeholder sensitization and Awareness	“Create awareness among stakeholders”, “Provide seminars/webinars”, “Continuous sensitization of stakeholders”	5
Transparent communication and collaboration	“Transparency in costing”, “Open communication with stakeholders”, “Work together with stakeholders”	3
Benchmarking and Accreditation	“Benchmark with similar organisations”, “Get the biobank accredited”, “Leverage oncology studies and other samples”	3
Affordability and Cost Concerns	“Lower costs for younger and upcoming scientists”, “Cost for non-MRC projects is high”, “Users expect even lower prices	3

	despite discounts”	
No Recommendations/ No Response	Participants wrote “No” or gave no feedback	5
Collaboration and Operational Awareness	“Biobank operations awareness and how we can work together”	1

Note: One participant’s comment fit under two schemes, so total responses exceeded number of participants (n= 20 coded responses from 19 participants).

Participants provided a range of recommendations for strengthening the cost recovery model at the biobank. As summarized in table 22 above, the most common suggestion was the need for greater stakeholder sensitization and awareness (n= 5). This included suggestions for conducting webinars and seminars and continuous education efforts to improve understanding of cost recovery mechanisms.

Several respondents highlighted issues around cost expectations and affordability (n= 2), particularly for early career researchers or users expecting lower rates despite existing discounts. Others emphasized the importance of transparency and open communication (n =3), calling for clearer pricing structures and collaborative engagement with stakeholders.

Benchmarking against similar institutions and obtaining accreditation were also noted (n =2), with the aim of aligning the biobank’s practices with recognized standards. One participant suggested expanding biobank infrastructure, including tissue storage facilities, to improve service capacity. Another recommended that stakeholder concerns be more actively integrated into policy design around cost recovery.

Five participants either did not provide a recommendation or explicitly stated “no suggestion”. Notably, one respondent provided a response that fit into two thematic categories, bringing the total number of coded recommendations to 20.

Additional stakeholder comments

Table 23: summary of additional comments on the cost recovery model at the biobank

Theme	Example content	Frequency
Need for stakeholder awareness and education	“The tool is an important aspect for the Biobank. However, it is misunderstood by some Biobank users. Creating awareness on this will make the process easier”.	2
Suggestion for cost adjustment or reconsideration	“The unit should reconsider 25% as overhead part of the cost recovery on those studies that may require storage”.	1
Collaboration for sample stability studies	“The Biobank should embark on collaborating with researchers to conduct sample stability studies”.	1
Clear explanation of the cost recovery model	“The cost recovery model should be explained well to all stakeholders of the unit”.	1

A total of 5 participants provided additional comments regarding the cost recovery model at the biobank. 2 participants emphasized the importance of raising awareness

and providing stakeholder education to improve understanding and acceptance of the cost recovery process.

One administrative staff member recommended reconsidering the 25% overhead applied to studies requiring storage. Another participant suggested collaboration with researchers to conduct sample stability studies, while one laboratory technologist highlighted the need for a clear explanation of the cost recovery model to all stakeholders. The remaining participants either did not respond or stated they had no additional comments.

CHAPTER FIVE

5.0 DISCUSSION

Introduction

This section interprets and contextualizes the findings of the study within existing literature and the broader framework of biobank sustainability. It explores key themes emerging from stakeholder responses regarding cost recovery, including levels of awareness, perceived necessity, challenges, and implications for biobank operations and sustainability. By drawing on both quantitative data and open-ended responses, the discussion aims to highlight areas of consensus, divergence, and opportunities for improvement in the current cost recovery model at the MRC/UVRI and LSHTM Biobank.

Awareness and Understanding of Cost Recovery

The findings reveal that while a majority of stakeholders agreed with the necessity of cost recovery at the biobank, there remains a substantial gap in understanding the concept and its implementation. This lack of clarity may contribute to uncertainty or resistance among certain groups, particularly among administrative staff and some researchers. Stakeholder awareness and education are critical to the successful implementation of biobank cost recovery systems, as misunderstandings can undermine trust and cooperation (17).

Stakeholders emphasized the need for sensitization efforts, clearer communication strategies, and training sessions. This aligns with literature suggesting that transparent communication and stakeholder engagement are fundamental to the sustainability of biobanks (18). Without adequate understanding, stakeholders may perceive cost recovery mechanisms as arbitrary or misaligned with research goals.

In addition, some participants recommended specific strategies such as the organization of seminars and the development of user-friendly guidelines to improve comprehension. These recommendations are consistent with previous studies highlighting the importance of continuous capacity building and stakeholder education in biobanking (19). Given that cost recovery touches on both ethical and

financial dimensions of biobanking, the importance of robust awareness campaigns cannot be overstated.

While a number of stakeholders indicated some awareness of cost recovery, the depth of understanding varied considerably. This aligns with findings that the successful implementation of biobank financial models depends not just on awareness, but on nuanced comprehension of operational and ethical dimensions (20). Inadequate understanding among key actors can contribute to misperceptions about the rationale behind cost recovery, as well as hesitancy in engaging with related procedures (21).

Moreover, stakeholder education plays a pivotal role. Literature from developing country contexts underscores the importance of targeted sensitization efforts, particularly in research environments where the concept of cost recovery is less established (22). Without tailored strategies to explain not only what cost recovery is but why it matters, buy-in remains limited, which can threaten the sustainability of shared research (23).

Efforts to improve understanding must also address the practical implications of cost recovery. For example, some participants in the study highlighted gaps in knowledge about how rates are calculated or why cost differentiation exists for certain user categories. This gap mirrors earlier findings which showed that transparency in biobank pricing structures is essential to avoid perceptions of inequity or financial exclusion (24).

In this context, ongoing engagement through workshops, transparent communication, and participatory policy development emerges as a best practice for improving comprehension and strengthening institutional support for cost recovery.

Perceived Importance and Need for Cost Recovery at the Biobank

The study found strong stakeholder support for the implementation of a cost recovery model at the Biobank. A majority of respondents agreed or strongly agreed that cost recovery is essential for the Biobank's long-term sustainability. This aligns with findings from previous research suggesting that cost recovery mechanisms are critical for ensuring the continuity and quality of biobank operations, especially in low-resource settings (25, 26).

Stakeholders expressed differing views regarding how the Biobank should prioritize cost recovery. While some believed that cost recovery should be a primary focus, others advocated for a balanced approach, one that prioritizes sustainability but also considers equitable access to services. These perspectives highlight the ethical and operational tensions involved in developing a cost recovery model that is both financially viable and socially responsible (27).

Interestingly, when asked whether Biobank clients would be willing to pay for services, responses were mixed. While a notable number of participants believed clients were willing to pay, many expressed uncertainty. This reflects a broader concern in the biobanking community about the potential risk of reduced access due to cost barriers (28). Such concerns emphasize the importance of stakeholder engagement and communication in shaping a cost recovery model that reflects both institutional needs and user realities.

Furthermore, the finding that very few participants reported choosing a Biobank based on cost suggests that, at present, financial considerations may not be the primary determinant of biobank use. However, as cost recovery is more rigorously implemented, this may change. This underscores the need for transparency in pricing structures and consistent messaging around the value of Biobank services.

Overall, these findings indicate broad conceptual support for cost recovery, tempered by concerns about affordability, equity, and user willingness to pay. It will be crucial for future strategies to integrate both sustainability and fairness, drawing on stakeholder feedback and real-world evidence.

These findings are in line with broader literature on biobank sustainability. Financial sustainability remains a top concern for biobanks globally, and cost recovery is one of the few practical mechanisms for generating consistent funding streams (28).

Moreover, ethical frameworks proposed by the OECD and the Global Alliance for Genomics and Health (GA4GH) encourage cost recovery approaches that are transparent and promote equity across different stakeholder groups (29).

The recognition of cost recovery as essential also reflects increasing awareness of the complexities of biobank operations. Literature suggests that while traditional funding sources such as grants or institutional support are often limited and uncertain, cost recovery allows for greater financial independence and continuity (30). Participants'

views mirror these concerns, revealing a shared understanding that cost recovery must be part of a broader sustainability plan rather than an isolated financial policy.

However, successful implementation depends on how cost recovery is perceived and communicated. Stakeholder buy-in, particularly from those who depend heavily on biobank services, hinges on trust, perceived fairness, and clarity about how funds are utilized (31). The mixed responses ranging from strong support to cautious optimism highlight the need for inclusive policy development that incorporates stakeholder feedback, particularly regarding affordability and access.

Participants also hinted at the need to balance financial goals with the biobank's mission. This tension is well-documented in global discourse around biobank governance. For example, cost recovery should not override the biobank's core ethical obligations, especially to promote open science and equitable access (32).

Awareness and Understanding of Cost Recovery Implementation at the Biobank

The findings revealed varying levels of awareness and understanding of how cost recovery is implemented at the biobank. While a number of participants indicated familiarity with the concept of cost recovery, fewer demonstrated a clear understanding of its practical implementation. This suggests a distinction between general awareness of the idea and deeper comprehension of its operationalization, which may have implications for stakeholder engagement and buy-in.

Limited understanding among some stakeholder categories particularly among administrative staff and external collaborators echoes concerns raised in previous literature about the challenges of implementing financial models in technical and scientific environments without adequate communication and training (33, 34). A lack of clarity about how cost recovery is executed can lead to scepticism, misinterpretation, or resistance, particularly if stakeholders are unclear on how cost decisions are made or how funds are allocated.

In contrast, stakeholders more closely involved in the day-to-day operations of the biobank, such as biobank staff and laboratory technologists, showed greater confidence in their understanding. This finding reinforces earlier research suggesting

that proximity to operational processes often correlates with higher levels of perceived transparency and understanding (35).

To improve awareness and stakeholder understanding, it may be useful to introduce structured orientation sessions, simplified cost recovery guides, and continuous engagement platforms where stakeholders can ask questions and provide feedback. Fostering understanding is not only critical to stakeholder satisfaction but also to the long-term sustainability and ethical integrity of cost recovery systems in research infrastructures (36).

Building on these findings, it is important to recognize that stakeholder understanding is not static but can evolve through targeted educational and engagement efforts. Previous studies have highlighted that even highly skilled professionals may struggle to navigate financial policies when those policies are not effectively communicated (37). Thus, biobanks must avoid assuming that professional expertise equates to familiarity with institutional cost models.

Moreover, insufficient understanding of implementation mechanisms may inadvertently create perceptions of exclusion or lack of transparency, particularly for those who feel distanced from decision-making processes. This can erode trust and compromise the cooperative spirit essential for shared resource infrastructures like biobanks (38). In addition to structured training, ongoing feedback loops such as quarterly stakeholder forums or user experience surveys could reinforce clarity and trust.

There is also a practical implication for the development of user-friendly documentation. Cost recovery policies often rely on technical language that may alienate or confuse stakeholders who are not finance-oriented. Literature suggests that visual tools such as flowcharts showing how cost recovery contributes to sustainability can help stakeholders grasp the logic behind the system (39). This can also minimize misunderstandings about how fees are set and how they relate to long-term biobank viability.

Finally, the varying degrees of understanding may signal the need for differentiated communication strategies. Internal stakeholders like biobank personnel may benefit from in-depth operational briefings, while external users may require concise, outcome-oriented messaging that explains how cost recovery supports service

reliability and sample quality. As previously emphasized, tailoring communication to the audience's context improves the uptake of institutional policy messages and encourages collaborative compliance (18).

Stakeholder Attitudes Toward Cost Recovery and Its Perceived Necessity

Stakeholders across all categories generally expressed strong support for cost recovery at the biobank, though the degree of agreement varied. A significant proportion either agreed or strongly agreed with the statement that cost recovery is necessary for the biobank's sustainability. This finding is consistent with global literature highlighting that financial sustainability is one of the most pressing challenges facing biobanks, particularly in low- and middle-income settings (40, 41). The high levels of agreement among biobank staff and researchers, in particular, may reflect their closer involvement with resource-intensive aspects of biobanking operations, and thus, their greater awareness of the financial realities involved.

However, a smaller group of respondents selected "neutral" or "strongly disagree," suggesting that not all stakeholders are fully convinced of the model's relevance or perhaps lack sufficient information to form a definitive opinion. This divergence in attitudes echoes findings from prior studies, where insufficient engagement or unclear cost frameworks led to stakeholder hesitancy and even resistance (42). When individuals do not perceive clear value for the costs involved, or if they feel excluded from the development of financial models, distrust and opposition can arise (43).

These findings reinforce the importance of early and continuous engagement with all categories of stakeholders in shaping and implementing cost recovery strategies. Creating a participatory environment allows for concerns to be addressed and increases the legitimacy and acceptability of the model (44). Additionally, these insights suggest a need for further sensitization and capacity building to close gaps in understanding and align perceptions with the financial imperatives of biobank management.

Furthermore, these attitudes highlight the potential influence of organizational culture and institutional support on stakeholder perceptions. Studies have shown that when institutions prioritize transparency, fairness, and shared ownership in their financial

strategies, stakeholders are more likely to perceive cost recovery not merely as a financial mechanism, but as a necessary strategy for sustaining scientific innovation and public trust (45, 18). Strengthening institutional communication around how cost recovery revenue is allocated, and emphasizing its role in enhancing services, infrastructure, and equity of access, may further improve buy-in.

Practical steps may also include involving stakeholders in developing cost allocation frameworks, offering tiered pricing models that consider different user capacities, and showcasing success stories where cost recovery has led to improvements in operations. Such measures not only address concerns but foster a sense of shared investment in the biobank's future. As the literature emphasizes, stakeholder trust and willingness to pay are closely tied to perceptions of procedural justice and benefit distribution (46).

Stakeholders' Understanding of How Cost Recovery is Implemented at the Biobank

Stakeholders' understanding of how cost recovery is implemented at the biobank varied significantly across different categories. While some respondents, particularly biobank staff, reported being "very aware," others, especially among administrative staff and researchers indicated limited or no understanding. This inconsistency highlights a potential communication gap between the biobank and its wider stakeholder community.

Understanding operational procedures such as cost recovery is essential for building trust and fostering compliance with institutional practices. Lack of clarity in implementation may lead to misinterpretation or resistance, particularly when financial contributions are expected from users (47). Previous studies suggest that transparency and participatory decision-making significantly enhance stakeholder buy-in and acceptance of cost-sharing mechanisms (48).

Additionally, the disparities in awareness may reflect broader structural issues within research institutions, where technical processes are often siloed and not adequately shared across departments (49). If cost recovery mechanisms are not communicated

effectively, they may be perceived as arbitrary or burdensome, thus undermining the biobank's sustainability goals.

To improve understanding and acceptance, targeted communication strategies are necessary. These could include regular stakeholder briefings, accessible policy documents, and practical workshops explaining the rationale, structure, and implications of cost recovery. Engagement must be continuous and responsive to the concerns raised by different stakeholder groups (50).

Furthermore, this limited understanding may influence how stakeholders perceive the value and legitimacy of the cost recovery model. When cost-related procedures are not clearly understood, users may feel that charges are inconsistently applied or unjustified, which can lead to reduced trust and diminished willingness to participate in biobank services (51). A transparent, well-communicated implementation process is essential not only for operational success but also for building long-term stakeholder relationships.

Differences in understanding may also reflect the nature of stakeholders' roles and their proximity to financial or operational decision-making. As highlighted, personnel directly involved in day-to-day biobank functions such as sample storage and data management are more likely to comprehend cost structures due to their exposure to internal workflows (52). Conversely, external collaborators or administrative teams may lack such insights, contributing to a knowledge gap that affects collaboration and compliance.

Efforts to bridge this gap must be inclusive and iterative. Rather than relying solely on top-down communication, biobank leadership can foster a two-way dialogue with stakeholders by incorporating feedback mechanisms, co-development of policies, and regular review sessions. These participatory approaches not only enhance understanding but also promote shared ownership of financial and operational strategies (53).

Ultimately, improving stakeholders' understanding of how cost recovery is implemented supports both ethical and practical goals. Ethically, it aligns with principles of transparency and accountability in research infrastructure governance. Practically, it can lead to smoother implementation, reduced conflict, and a more sustainable biobank operation over time (36).

Do Stakeholders Think Cost Recovery is Essential for Sustainability?

Stakeholders' views indicate strong overall support for cost recovery as a necessary strategy to ensure the long-term sustainability of biobank operations. This finding aligns with existing literature, which emphasizes that financial self-sufficiency is increasingly critical for biobanks, especially as external funding becomes more competitive and inconsistent (54, 55).

The strong endorsement from biobank staff and researchers may reflect a deeper understanding of the infrastructure and costs required to maintain high-quality biobanking services, including storage, equipment, data management, and regulatory compliance (56). Their positions often involve direct exposure to the challenges of securing ongoing funding and ensuring uninterrupted service provision.

However, the presence of some neutral or opposing views particularly among administrative staff and suppliers highlights the need for continued stakeholder education and transparent communication around the purpose, benefits, and implementation of cost recovery. It is possible that concerns around affordability or unclear policies could influence their hesitancy to fully support cost recovery, as noted in similar studies on stakeholder perceptions of biobank financing (57). Furthermore, this division suggests that while there is high-level consensus on the need for cost recovery, there may be less agreement on how it should be implemented or who should bear the cost.

Furthermore, the general agreement among stakeholders may be indicative of an increasing awareness of the financial realities facing biobanks, particularly in low- and middle-income countries where reliance on donor funding is less sustainable over time. As more institutions shift towards hybrid funding models, cost recovery is increasingly viewed not only as a financial mechanism but also as a governance strategy that reinforces institutional autonomy and resilience (58).

Nevertheless, successful implementation requires more than just ideological support. Studies show that even when stakeholders agree in principle with cost recovery, operational challenges such as inconsistent fee structures, lack of training, or limited consultation can undermine support in practice (18). Involving stakeholders early in

the design and rollout of financial models can mitigate this gap between endorsement and effective uptake.

Additionally, the concern raised by certain stakeholder groups around affordability reflects wider ethical tensions in biobank management. Ensuring equitable access while recouping costs necessitates a sensitive balance, one that safeguards inclusivity without compromising sustainability (59). Tiered pricing models or subsidized access for specific groups may help address these tensions, allowing cost recovery strategies to be both fair and financially viable.

Looking ahead, biobanks must not only communicate the necessity of cost recovery but also demonstrate the value it brings and how it translates into improved services, better infrastructure, and enhanced long-term access for all stakeholders.

Transparency in fund allocation, stakeholder feedback mechanisms, and regular impact reporting can play critical roles in maintaining trust and reinforcing commitment to sustainable biobanking practices (60).

Should the Biobank Prioritize Cost Recovery or Focus on Providing Free Services?

The diverse range of responses to this question underscores the tension between financial sustainability and equitable access, a longstanding debate in biobank management (61). Most stakeholders advocated for a balanced strategy, suggesting that while cost recovery is necessary, it should not come at the expense of accessibility, particularly for public health or academic users with limited budgets.

This preference for balance reflects growing recognition that biobanks function not only as service providers but also as public goods supporting health research and innovation. Studies have noted that when cost recovery mechanisms are designed without considering equity, they risk excluding smaller institutions or early-career researchers from accessing critical biospecimens (54).

Meanwhile, those who prioritised cost recovery may have a stronger focus on ensuring operational continuity, especially in contexts where donor funding is declining or unpredictable. Their responses may reflect the view that financial sustainability is foundational for any long-term benefit to research and public health.

Ultimately, these findings suggest that a tiered pricing system, subsidies for early-career scientists, and transparent cost breakdowns could help resolve the apparent contradiction between sustainability and access. A model that reflects both economic and ethical considerations may be the most widely acceptable strategy among stakeholders (62).

Furthermore, the debate between prioritizing cost recovery and offering free access mirrors broader ethical discussions in global health research infrastructure. Scholars have long emphasized the need for biobanks, especially those operating in LMIC's to uphold principles of equity, justice, and scientific inclusivity (63). In this context, the preference for a balanced approach is not only pragmatic but ethically sound, reflecting the biobank's dual mandate: to sustain itself financially while contributing to public health advancement.

In practical terms, stakeholders who favoured prioritizing cost recovery may be acutely aware of the rising costs of maintaining biobank operations such as sample preservation, staffing, equipment, and IT infrastructure. Without some level of revenue generation, these services could stagnate or collapse, ultimately harming all potential users (56). However, a purely market-driven approach could inadvertently entrench inequalities, especially for underfunded researchers or community-based initiatives.

Therefore, hybrid models such as tiered pricing, institutional subsidies, or public-private partnerships are increasingly being proposed as mechanisms that respect both sustainability and inclusiveness (64, 65). Stakeholders' emphasis on fairness and flexibility reinforces this direction, suggesting that any cost recovery system must be clearly explained, widely communicated, and periodically reviewed to ensure it does not place undue burden on certain groups.

Transparency in how recovered costs are reinvested into biobank services may also foster greater trust and continued collaboration. As recent research points out, when users see the value added such as better-quality control, faster turnaround, or expanded sample access, they are more likely to accept financial contributions as a legitimate part of accessing biobank services (35).

Stakeholder Perceptions of Challenges in Implementing Cost Recovery at the Biobank.

Several challenges to implementing cost recovery were identified across stakeholder groups. The most frequently mentioned issues included limited understanding of the model, lack of stakeholder funding, resistance from certain user groups, and affordability concerns. These concerns are consistent with previous studies that highlight stakeholder hesitancy when financial policies are introduced in collaborative research environments (66, 67).

A significant number of respondents pointed to limited understanding of cost recovery, indicating that even when the concept is introduced, its nuances are not always well communicated or internalized. This mirrors the findings that insufficient education around biobank cost structures often leads to confusion, unrealistic expectations, or disengagement (68).

Affordability also emerged as a prominent concern, particularly from administrative staff and researchers. This aligns with global literature pointing to the financial constraints faced by research institutions in low- and middle-income countries, which may deter sample access if pricing is not adapted to local realities (69,70).

Resistance from stakeholders, whether due to lack of clarity, discomfort with pricing, or institutional inertia was another recurring issue. Stakeholder resistance is often rooted in ethical concerns, especially when access to biological samples appears to be determined by financial capacity rather than research merit (67).

Taken together, these challenges suggest that the success of cost recovery models depends not just on having policies in place, but on strategic communication, adaptive pricing, and stakeholder involvement throughout the process. Tailoring recovery mechanisms to institutional and national contexts will be critical to ensuring both sustainability and equity.

Perceived Impacts of Cost Recovery on Biobank Operations.

Participants identified a range of perceived impacts associated with implementing cost recovery at the biobank. The most frequently mentioned positive impacts included

improved sustainability of operations, greater access to services, enhanced efficiency, and innovation and expansion. These responses reflect broad recognition among stakeholders that cost recovery can play a transformative role in strengthening the biobank's long-term functionality.

This aligns with literature that highlights cost recovery as a key pillar of financial sustainability in biobanking, especially as donor funding becomes increasingly competitive (71). In particular, respondents noted that cost recovery mechanisms could enable the biobank to allocate resources more efficiently, invest in infrastructure upgrades, and better respond to emerging research needs. As previous studies have shown, strategic reinvestment of recovered funds can support innovation, such as new sample processing capabilities, expanded storage, and digital system upgrades (72).

However, concerns were also raised about potential negative consequences. Some respondents highlighted the risk of reduced access to services due to increased costs, particularly for early-career researchers or underfunded institutions. This reflects a well-documented tension in the biobanking literature, where cost recovery can inadvertently become a barrier to access if not carefully designed (73). A similar challenge was noted in other low- and middle-income contexts, where users' ability to pay may vary significantly, potentially leading to disparities in service utilization (74).

Taken together, these findings suggest that while stakeholders acknowledge the operational benefits of cost recovery, its design must account for equity, flexibility, and transparency. Tiered pricing, subsidies for specific groups, and ongoing consultation with stakeholders may help mitigate access concerns while preserving the financial advantages of the model. A well-implemented cost recovery system is thus not only an economic necessity but also an opportunity to build a more inclusive and resilient biobank infrastructure (75).

Willingness of Stakeholders to Pay for Biobank Services.

The survey revealed that a majority of stakeholders expressed a willingness to pay for biobank services, although some respondents, particularly administrative staff and

laboratory technologists indicated uncertainty. This finding reflects a cautiously optimistic view of cost recovery, where stakeholders recognize the value of the biobank but may still be unclear about their financial obligations or capacity to contribute.

The willingness to pay is a critical factor for the sustainability of biobanking operations, especially in low- and middle-income countries where external funding may be limited or inconsistent (76). Stakeholders who are more directly involved in research or biobank operations, such as biobank staff and researchers, showed higher willingness, possibly due to their greater appreciation of the costs involved in maintaining high-quality biospecimen services. This trend is echoed in other studies where awareness of operational costs has been linked to higher acceptance of cost-sharing mechanisms (77).

However, the presence of uncertainty among a significant portion of respondents suggests that communication and transparency about pricing models and their rationale may need to be strengthened. Concerns may stem from fears of unaffordability, lack of clarity about what is being paid for, or uncertainty about how funds will be used (61). As such, willingness to pay does not automatically translate into ability or readiness to pay.

To address this, biobanks might consider implementing sliding-scale pricing models based on the stakeholder's affiliation or the type of project being undertaken. Additionally, ensuring open channels for discussion on pricing and service expectations can help build trust and support for cost recovery systems. The literature supports that participatory and transparent financial models are more likely to gain widespread acceptance across stakeholder groups (74).

Stakeholders' Experiences with Comparing Biobank Costs Before Selecting Services

Stakeholder responses to the question, "When looking for samples at a Biobank, have you ever compared costs and decided for the cheapest Biobank?", revealed that cost is not always the primary determinant in decision-making for most users. The majority of stakeholders reported that they had not actively compared biobank prices before

selecting a service, suggesting that factors such as sample quality, familiarity, trust, or convenience may weigh more heavily in selection than price alone.

This finding is noteworthy in the context of cost recovery implementation. While pricing is a core component of sustainability, it may not be the most salient factor from the client's perspective. Similar studies have shown that researchers often prioritize sample availability, reliability, and compliance with ethical standards over price when selecting biobank services (78). In environments where only a limited number of biobanks are available or where one institution is perceived as more reputable there may be little incentive to comparison shop, even if cost recovery introduces additional charges.

The implications of this are two-fold. First, it suggests that transparent pricing and value communication may be more important than competitive pricing alone. If stakeholders are not price-sensitive but care about perceived fairness and clarity, then cost recovery systems must emphasize justification of charges and the value added through services. Second, the data underscores the potential to maintain stakeholder loyalty even with modest cost increases provided that service quality and communication remain strong.

Going forward, biobank management teams could benefit from conducting client satisfaction surveys to understand the full range of factors influencing user choices. Doing so would inform pricing models that are both sustainable and responsive to stakeholder values.

Final Reflections and General Sentiments Toward Cost Recovery

Although not all participants provided detailed suggestions or recommendations, several shared general reflections on the cost recovery model. A few respondents emphasized the importance of creating awareness and improving communication between the biobank and its users. One participant highlighted the need for presentations and sensitization sessions to help staff and researchers better understand the operations and objectives of the biobank. Another emphasized that while cost recovery is a valuable tool, it is often misunderstood, a sentiment that echoes findings discussed in earlier themes.

Some stakeholders also noted concerns about specific elements of the cost structure, such as the appropriateness of certain overhead charges, and emphasized the importance of stakeholder collaboration in shaping future directions. The absence of responses from several participants further underscores the need for ongoing engagement and education around cost recovery concepts.

These reflections, although not always detailed, contribute to the overall understanding of stakeholder attitudes. They reinforce the broader conclusion that for cost recovery to succeed, it must be transparent, inclusive, and responsive to the diverse needs and concerns of its user base (79).

5.1 Conclusion

This study explored stakeholders' awareness, attitudes, and perceptions toward cost recovery at the MRC-UVRI and LSHTM Biobank in Uganda. The findings reveal a moderate level of familiarity with cost recovery among stakeholders, with significant variation in understanding and support based on professional role and engagement with the biobank. While many participants acknowledged the importance of cost recovery for sustainability, concerns around affordability, transparency, and stakeholder engagement were prominent.

Participants emphasized the need for improved communication, clearer policies, and capacity building to increase buy-in and reduce resistance. Recommendations included continuous stakeholder sensitization, subsidized pricing for specific groups, and strategic partnerships to support financial sustainability without compromising access.

Overall, the results highlight the importance of a balanced and inclusive cost recovery model that accounts for the diverse needs of users, promotes financial sustainability, and upholds the biobank's mission to support equitable and impactful research. This study contributes to ongoing conversations about sustainable biobanking practices in low-resource settings and provides actionable insights for the development and refinement of cost recovery models in similar contexts.

As biobanking continues to expand across Africa, a context-specific, ethically grounded, and financially viable cost recovery approach will be essential to ensure both scientific advancement and equitable access.

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ANNEX

Interview guide

Stakeholders' perceptions and attitudes towards cost recovery at Medical Research Council/Uganda Virus Research Institute and London School of Hygiene & Tropical Medicine biobank in Uganda.

Introduction

This survey seeks to understand your perceptions, attitudes and knowledge regarding cost recovery practices at the MRC/UVRI and LSHTM Biobank in Uganda. Your participation is valuable in helping improve the sustainability and accessibility of the biobank resource at the unit. The survey is anonymous and will take approximately 10-15 minutes to complete.

Demographic data.

1) What is your gender identity?

- Female
- Male
- Prefer not to answer

2) What is your age?

- Below 24
- 25-34
- 35-44
- 45-54
- 55-64
- Above 64
- Prefer not to answer

3) What is your role at the biobank or in relation to its operations?

a) Role at the biobank

- o Biobank Manager
- o Biobank staff
- o Researchers
- o Project leaders

- o Administrative staff
- o Quality/Risk management
- o Data management
- o Laboratory technologist
- o Information Technology specialist

b) Role related to the biobank operations

- o Regulatory officer
- o Compliance officer
- o Equipment/ consumables supplier
- o Software solution provider
- o Other (please specify)

Knowledge of Cost Recovery at the Biobank

4)How familiar are you with the concept of cost recovery at the biobank?

- o Very familiar
- o Somewhat familiar
- o Not very familiar
- o Not familiar at all

5) To what extent do you understand how cost recovery is implemented at the biobank

Very well

To some extent

A little

Not at all

Not sure

6) Do you know what services or activities at the biobank are subject to cost recovery?

Yes

No

Not sure

7) What types of costs do you think are included in the Biobank cost recovery model?

(Select all that apply)

Storage and maintenance of biological samples

Data management costs

Staff salaries

Maintenance of biobank infrastructure

Equipment and laboratory expenses

Regulatory compliance and legal fees

Administrative overhead

Access to biobank services

Research support

Other (please specify) _____

8) How aware are you of the fees for biobank services?

- o Very aware
- o Somewhat aware
- o Not aware at all
- o Not sure

9) How would you cost the following biobank services?

a) Sample Storage (per year per sample)

- £3.00- £3.5 per sample per year
- £2.00-£2.5 per sample per year
- £2.00-£2.50 per sample per year
- £1.00-£1.50 per sample per year
- £0.20-£ 0.99 per sample per year
- Not sure

b) sample retrieval

- £1.0-£1.50 per sample
- £0.02-£ 0.10 per sample
- Not sure

10)What do you think is the most important factor when considering cost recovery for the

biobank?

- o Affordability
- o Sustainability of biobank operations
- o Ethical considerations
- o Transparency in pricing
- o Other (please specify) _____

Perceptions and Attitudes towards Cost Recovery

11) How do you perceive the need for cost recovery at the biobank?

- Strongly agree
- Agree
- Neutral
- Disagree
- Strongly disagree

12) Is cost recovery essential for the sustainability of the biobank?

- Strongly agree
- Agree
- Neutral
- Disagree
- Strongly disagree

13) When looking for samples at a biobank, have you ever compared costs and decided for

the cheapest biobank?

- Yes
- No

14) Do you think there should be different cost recovery rates for academic scientists versus

industrial researchers?

- Yes
- No

15)What do you think is the impact of implementing cost recovery at the biobank on its operations?

(Select all that apply)

- Improved sustainability of biobank operations
- Increased research opportunities
- Greater access to biobank services
- Innovation and expansion
- Optimal resource use
- Improved efficiency
- Reduced access due to increased costs
- Other (please specify) _____

16)Do you think biobank clients are willing to pay for services at the biobank?

- Yes
- No
- Unsure

17)What are the potential challenges of implementing cost recovery at the biobank?

(Select all that apply)

- Lack of funding from stakeholders
- Affordability concerns for certain stakeholders
- Ethical concerns
- Limited understanding of cost recovery
- Resistance from stakeholders
- Other (please specify) _____

18)In your opinion, should the biobank prioritize cost recovery, or should it focus on

providing services at no cost to users?

- o Prioritize cost recovery
- o Focus on providing services at no cost
- o A balance between the two
- o Not sure

Suggestions for Improvement

19) Do you have any recommendations for improving the cost recovery model at the biobank?

20) Any additional comments or thoughts on the cost recovery model at the biobank?

Thank you for taking the time to complete this survey. Your responses will contribute to valuable

insights and information on how to improve the MRC/UVRI biobank operations.