

Master Thesis

Perception of Biobanking among sample collectors, sample transporters, laboratory staff and biobank staff at Medical Research Council/Uganda Virus Research Institute and London School of Hygiene & Tropical Medicine Uganda Research Unit

Submitted by

Phillis Babirye

For the academic degree of

**Master of Science Biobanking
(MSc)**

at the

Medical University of Graz

executed as part of the

University Training Course Master of Science in Biobanking

Under the supervision of

Berthold Huppertz

Submitted 2020

Uganda, 05/01/2021

Statutory Declaration

I declare on my honor 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 05/01/2021

Phillis Babirye eh

Acknowledgments

“Now to him who is able to do immeasurably more than all we ask or imagine, according to his power that is at work within us”. (*New International Version*, Ephesians 3:20).

All Glory belongs to God.

I would like to thank Prof Berthold Huppertz, Karine Sargsyan and Gabrielle Harlt for all the support and guidance they provided to me to achieve the MSC in Biobanking.

Special thanks go to Dr David Kaawa-Mafigiri, Andrew Ssemata and Denis Ndekezi for their endless help.

Abstrakt

Hintergrund: Die Miteinbeziehung von Teilnehmern und Stakeholdern in die Forschungsaktivität von Biobanken ist derzeit sehr gefragt. Es wurden Forschungsarbeiten durchgeführt, um die Meinungen von Forschern, Teilnehmern, REC-Mitgliedern (Research Ethics Committee) und Patienten zum Thema Biobanking zu untersuchen. Allerdings gibt es bisher nur wenige Forschungsarbeiten, die sich mit den Ansichten von Fachleuten im Bereich Biobanking befassen. Ziel der Studie war es, den Wissensstand und die Wahrnehmung von Biobanking zu verstehen.

Methodik: Diese Querschnittstudie nutzte eine qualitative Forschungsmethodik, um die Einschätzung und den Wissensstand zum Thema Biobanking von Mitarbeitern, welche die Proben sammeln und transportieren, von Labormitarbeitern und generell von Biobankmitarbeitern des “Medical Research Council/Uganda Virus Research Institute” und der “London School of Hygiene & Tropical Medicine Uganda Research Unit” zu untersuchen. Für die Informationssammlung wurde ein ausführlicher Interviewleitfaden verwendet und alle Interviews wurden mittels Audioaufnahmen aufgezeichnet.

Ergebnisse: An der Studie nahmen insgesamt 17 Personen teil. Mehrere Teilnehmer (70,6%) stellten eine Verbindung zwischen Biobanken und der Lagerung von Proben für die zukünftige Verwendung und für Forschungszwecke her. 82,4% der Teilnehmer assoziierten eine Biobank mit einer Einrichtung, die sich mit der Bearbeitung von Proben befasst und die über unterschiedliche Lagereinrichtungen und kontrollierte Temperaturbedingungen verfügt. Die Teilnehmer waren der Ansicht, dass in Uganda weitere Biobanken benötigt werden würden. 76,5% der Teilnehmer waren ebenso dazu bereit Proben zu spenden und 52,9 % unterstützten den Versand von Proben von Uganda ins Ausland.

Diskussion: Trotz des Wissens der Teilnehmer über Biobanken schien es eine Lücke im Bewusstsein für alle Biobank-Aktivitäten zu geben. Obwohl viele Empfehlungen vorgeschlagen wurden, wäre es wichtig, dass Biobanken alle Aktivitäten transparent ausführen und darüber informieren, welchen Leitlinien sie folgen. Die Anliegen der Befragten zu verstehen und zu berücksichtigen, kann dazu beitragen, Biobanking in Uganda und im “Medical Research Council/Uganda Virus Research

Institute” und in der “London School of Hygiene & Tropical Medicine Uganda Research Unit” zu verbessern.

Abstract

Background; Involving participants and stakeholders in biobank research activities is currently at a high demand. There has been research carried out to explore the views towards biobanking among researchers, participants, REC (Research Ethics Committee) members and patients. However, there has not been much research that has been done to explore views of professionals in the biobanking field. The aim of this study was to understand the level of knowledge of biobanking and the perceptions towards biobanking.

Methods; This cross-sectional study used a qualitative research methodology to explore the perceptions and the level of knowledge towards biobanking among sample collectors, sample transporters, laboratory staff and biobank staff at Medical Research Council/Uganda Virus Research Institute and London School of Hygiene & Tropical Medicine Uganda Research Unit. An in-depth interview guide was used to collect the information, and all interviews were audio recorded.

Results; A total of 17 participants took part in this study. Several participants (70.6%) associated biobanking to the storage of samples for future use and research purposes. 82.4% participants also linked a biobank to a facility that deals with handling of samples and has different storage equipment and controlled temperature conditions. Participants felt that more biobanks were needed in Uganda. 76.5% were also willing to donate samples and 52.9% supported shipping of samples out of Uganda.

Conclusion; Despite their knowledge about biobanks, there seemed to be a gap in the awareness of all biobanking activities. Although many recommendations were suggested, one important aspect to take from all that would be that the biobanks should be transparent about the activities they carry out and what guidelines they follow. Understanding the concerns raised by the respondents and putting them into consideration can help improve on biobanking in Uganda and at Medical Research Council/Uganda Virus Research Institute and London School of Hygiene & Tropical Medicine Uganda Research Unit.

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Abbreviations

Abbreviation	Explanation
COVID 19	Coronavirus Disease 2019
CPHL	Central Public Health Laboratories
HIV	Human Immunodeficiency Virus
H3Africa	The Human Hereditary and Health in Africa
IBRH3AU	Integrated Biorepository of H3Africa Uganda
IHVN	Institute of Human Virology Nigeria
LIMS	Laboratory Information Management System
LMICs	Low-and middle-income countries
LSHTM	London School of Hygiene & Tropical Medicine
MRC	Medical Research Council
NIH	National Institute of Health
PBMCs	Peripheral Blood Mononuclear Cells
PEP	Post-Exposure Prophylaxis
PI	Principal Investigator
PPE	Personal Protective Equipment
REC	Research Ethics Committee
SOP	Standard Operating Procedure
STI	Sexually Transmitted Disease
UK	United Kingdom
UNCST	Uganda National Council for Science & Technology
UTI	Urinary Tract Infection
UVRI	Uganda Virus Research Institute
UWEC	The Uganda Wildlife Education Centre

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1.0 Introduction

Biobanking involves the collection of bodily fluid or tissue samples to support research (1). A biobank was defined by De Souza and Greenspan (2) as a biorepository which accepts, processes, stores and distributes biospecimens and associated data for use in research and clinical care. Biobanks can have specimen collections of plants, animals or humans.

Biobanking at Global level

The setting of biobanking in the European community has immensely developed (3). In the midst of developing biobanks, there have been concerns of the public about different issues that have been observed (4). Involving participants and stakeholders in biobank research activities is currently at a high demand (3). Maintaining the trust the public has towards biobanks should be considered during governance of the biobanks. Age, ethnicity and race are some of the contributing factors towards the attitudes that people have about participating in research studies and even donating biospecimens (4). The majority of the research studies done to explore public views on biobanking have shown that the public supports biobank activities (5).

Biobanking at Low -& Middle -Income Countries (LMICs) level

Low- and middle-income countries profit less than high income countries from genetic research. This has been attributed to lack of biobanks and big cohort studies (6). Lack of awareness of the benefits of biobanks and financial constraints remain a challenge in low income countries and hinder the establishment and maintenance of appropriate infrastructure for research activities, including cold storage facilities, electronic databases and quality assurance tools (7).

For decades, Africa was inadequately represented in the field of biobanking. Early initiatives such as the MalariaGenNetwork comprised a few biobanks which served as channels of transport for samples to more developed countries (8). The Human Hereditary and Health in Africa (H3Africa) initiative was launched in June 2010 as a joint venture by the National Institute of Health (NIH) and the Wellcome Trust (9). The H3Africa consortium currently has over 500 members from 30 African countries and supports 51 population-based genomic studies aimed at assessing the influence of genes and the environment on health and diseases (10). Biospecimens from the H3Africa consortium are managed by the H3Africa Biorepository Program which currently constitutes three biorepositories in Nigeria (Institute of Human Virology Nigeria (IHVN), South Africa

(H3Africa Biorepository at Clinical Laboratory Services, University of the Witwatersrand) and Uganda (Integrated Biorepository of H3Africa Uganda [IBRH3AU], at Makerere University College of Health Sciences) (11).

Many institutes in Africa currently lack national legislation or guidelines on the usage of stored biospecimens (9). A review of the ethical guidelines for genetic research and biobanking in 22 African countries by de Vries et al. (12) in 2017 revealed the lack of regulation of genomic research in Africa. Guidelines were either outdated, still in progress or completely absent. Without the guidance of a framework, researchers and ethics committees are likely to make impulsive decisions which hardly reflect ethical conduct (12). These strains are additionally exacerbated by the lack of research on the perceptions of people in Africa towards the storage and use of their biological data (9).

Biobanking at Uganda level

In 2016, the National Biorepository of the Uganda Government, under the custodianship of Central Public Health Laboratories (CPHL), suggested to start up a biorepository for proper management and storage of biospecimens to support future research and promote local and international collaborations (13). Currently, there has been no mapping done for the available biorepositories/biobanks in Uganda (13).

The majority of biobanks in Uganda are situated within research institutions. The establishment, accreditation and management of biobanks and biorepositories in Uganda is regulated by the Uganda National Council for Science & Technology (UNCST). UNCST provides national policies and guidelines that stipulate respect for research participants and protection from associated risks, beneficence and engagement of relevant stakeholders including research participants, Research Ethics Committees (RECs) and other regulatory authorities. However, local expansion of biobanks in Uganda continues to face some difficulties. Unavailability of access to high quality, well identified samples and the absence of a proper regulatory and governance structure have been identified as potential barriers to biobank research and the growth of biobanks in Uganda (14).

Established at the request of the Ugandan Government in 1988, to the United Kingdom (12) 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 (15, 16).

1.1 LITERATURE REVIEW

A publication by the European Commission listed the essential roles of a biobank as (a) collection and storage of biospecimens with their data, (b) to take project collections as long term or constant rather than static, (c) to be involved at the start of biospecimen collection of current and future studies, (d) to protect participant privacy through pseudonimization, and (e) to develop protection procedures for participant rights and stakeholder interests (17).

Globally, there have been several studies done on attitudes of biobanking. In one study (18), a list of some of the earlier studies exploring perspectives of biobanking showed that they were carried out among participants (19,20), among members of REC (21), among patients (22), among the media (23) and some among researchers (24-30).

Most recently, Domaradzki and Pawlikowski (5) summarized the present research publications on social attitudes towards biobanking. From the 61 publications selected in this study, the results showed the following number of countries that have carried out research on the biobanking social attitudes. In North America there were twenty-four studies, in Pan-European countries there were two studies, fifteen studies in different European countries, ten studies in Asia, four studies in Africa and one in Australia. The four studies in Africa were conducted in Nigeria (1 study), Uganda (1 study) and Egypt (2 studies). The study conducted in Uganda, focused on the views of Ugandans who had enrolled a child in a drug efficacy study for malaria. In this study they surveyed the views towards research on stored biological samples (31). 4% of the respondents did not trust the researchers because they believed the samples would be used for non-research related activities or even sold. 85% agreed to the use of the child's sample for research on HIV, 81% agreed to the use of the samples in research concerning any other disease other than HIV and 94% agreed to sharing of the child's samples with Tanzanian or Kenyan researchers.

Ssali et al. (32) explored the perceptions and experiences of Ugandan individuals who were taking part in two HIV clinical trials. One of the volunteers interviewed in this study suggested that during the informed consent process, the participant should be given more time to think about the provided information and discouraged asking of questions right

after being informed of the study. Another suggestion from a different volunteer was about the researchers providing understandable information about the study.

1.2 PROBLEM STATEMENT

Success of a biobank is dependent on several factors. There has been research carried out to explore the views towards biobanking among researchers, participants, REC members and patients (18). However, there has not been much research that has been done to explore views of professionals in the biobanking field (3). There is need to explore perceptions of biobanking among sample collectors, sample transporters, laboratory staff and biobank staff because they are critical in the success of biobanking and are involved in the day to day activities of a biobank in terms of sample collection, sample transportation, sample processing, sample testing, sample storage and sample retrieval.

The aim of this study is to understand the level of knowledge of biobanking and the perceptions towards biobanking among sample collectors, sample transporters, laboratory staff and biobank staff at MRC/UVRI & LSHTM Uganda Research Unit. The information obtained from this research study will help the organization and policymakers to better coordinate their efforts in better management of the samples. It can also be used to improve biobanking policies, processes, systems and procedures in Uganda. If biobank management in Uganda is poor, then sample collections, confidentiality of research participants, research studies and even research outcomes could be jeopardized. Participant involvement and stakeholder engagement is required (3).

1.3 OBJECTIVES

- 1 To explore the level of knowledge of biobanking among sample collectors, sample transporters, laboratory staff and biobank staff at MRC/UVRI & LSHTM Uganda Research Unit
- 2 To explore the perceptions towards biobanking among sample collectors, sample transporters, laboratory staff and biobank staff at MRC/UVRI & LSHTM Uganda Research

1.4 RESEARCH QUESTIONS

- 1 What is the level of knowledge of biobanking among sample collectors, sample transporters, laboratory staff and biobank staff at MRC/UVRI & LSHTM Uganda Research Unit?

2 What are the perceptions towards biobanking among sample collectors, sample transporters, laboratory staff and biobank staff at MRC/UVRI & LSHTM Uganda Research Unit?

1.5 SIGNIFICANCE OF THE STUDY

This study seeks to gain knowledge on the perception of biobanking which will enable stronger engagement, commitment and advocacy with stakeholders to manage biobanks effectively. Furthermore, the findings will fill the knowledge gap among the specialists in the field of biobanking.

2.0 METHODS

This cross-sectional study used a qualitative research methodology to explore the perceptions and the level of knowledge towards biobanking among sample collectors, sample transporters, laboratory staff and biobank staff at MRC/UVRI & LSHTM Uganda Research Unit. A semi-structured data collection tool was used to gather the information.

2.1 Study area

The study was carried out at Medical Research Council/Uganda Virus Research Institute and London School of Hygiene & Tropical Medicine (MRC/UVRI & LSHTM) Uganda Research Unit based in Entebbe at the UVRI campus.

2.2 Participant enrolment

The focus of this study was to collect data from sample collectors, sample transporters, laboratory staff and biobank staff. These groups of people were targeted because they were believed to be a contributing factor towards the success of biobanking. And since they are involved in the day to day activities of a biobank in terms of sample collection, sample transportation, sample processing, sample testing, sample storage and sample retrieval at MRC/UVRI & LSHTM Uganda Research Unit, they were considered to have very important opinions regarding this study. Each potential participant was sent an email detailing the study information. One-to-one interviews with willing participants were arranged and all participants were required to sign an informed consent form before the interview. A total of 17 participants took part in this study. There were 3 sample collectors, 3 sample transporters, 8 laboratory staff and 3 biobank staff that were interviewed.

2.3 Data collection

An in-depth interview guide (appendix A) was used, and all interviews were audio recorded.

2.4 Data analysis

Upon transcription of audio data, and assignment of name to the MS word file which matches the name of the corresponding audio file, data was transcribed verbatim. Qualitative data was organized and managed using manual coding methods. Data from the interviews was coded and analysed through thematic Analysis approach. The thematic analysis helped to provide a highly systematic method of categorizing and organizing data

according to key themes, concepts and emergent categories. To determine the common sense in the respondents replies, the main topics that emerged from each theme and the total number of respondents under those particular topics were presented in tables.

2.5 Ethical considerations

Ethical approval to conduct this study was sought from the Research and Ethics committee of Uganda Virus Research Institute and approval from Uganda National Council for Science and Technology (Reference number: SS469ES; appendix B). Written informed consent was attained from the participants before taking part in the study, and data collected will be kept with utmost confidentiality.

3.0 RESULTS

A total of 17 participants; 3 sample collectors, 3 sample transporters, 8 laboratory staff and 3 biobank staff were interviewed in this study. The socio-demographic information of the participants is summarized in Table 1.

Table 1

Socio-demographic information	Sample collector	Sample transporter	Laboratory staff	Biobank staff	Total
Number (n (%))	3 (17.6)	3 (17.6)	8 (47.1)	3 (17.6)	99.9
Gender					
Male	2 (11.8)	3 (17.6)	5 (29.4)	1 (5.9)	64.7
Female	1 (5.9)	0	3 (17.6)		35.3
Education level					
Higher national certificate	0	1 (5.9)	0	0	5.9
Higher national diploma	2 (11.8)	0	0	0	11.8
Bachelor's degree	1 (5.9)	2 (11.8)	7 (41.2)	3 (17.6)	76.5
Years in profession					
6-12 months	0	0	1 (5.9)	0	5.9
1-5 years	1 (5.9)	1 (5.9)	5 (29.4)	1 (5.9)	47.1
6-10 years	1 (5.9)	0	0	2 (11.8)	17.7
11-15 years	0	1 (5.9)	1 (5.9)	0	11.8
16-20 years	0	1 (5.9)	1 (5.9)	0	11.8
21-25 years	1 (5.9)	0	0	0	5.9

Table 1: This table displays the socio-demographic information of the participants including gender, education level and years in profession.

The majority of the participants were aware of what biobanking is about, with each uniquely describing what a biobank is. Lastly, communication of research outcomes by researchers to sample collectors, sample transporters, laboratory staff and biobank staff was considered an important practice as a way of team building. Each of the themes and subthemes presented in Table 2 is described in detail below.

Table 2

Theme	Sub-theme
Knowledge about Biobanking	What they know about Biobanking
	Description of a biobank
	Availability of biobanks in Uganda
Perceptions towards Biobanking	Thoughts about animal and plant samples
	How they feel when human samples are collected and stored
	Relevance of biobanks
	Participation in sample donation
	Concerns they have about the collection and use of samples for research
	Challenges of biobanking in Uganda
	Concerns received from research participants or the public relating to collection and use of human samples for research
Other factors affecting collection, storage and use of samples for research purposes	
Sample and sample data sharing	How do you feel about sample and sample data sharing with other researchers
	Do you think they should share samples and sample data with only local researchers or even out of Uganda?
	Opinion on the communication of research results from biobanked samples to participants
Recommendations to improve on Biobanking	In Uganda
	Institutional

Table 2: Themes and subthemes that emerged from the collected data.

Theme 1: Knowledge about Biobanking.

Table 3 shows a summary of the main topics that emerged from theme 1 and the number of participants that thought that way.

Table 3

Theme	Topics	Number of respondents
Knowledge about biobanking	Biobanking is associated with the storage of samples for future research use	12
	A biobank is a facility that deals with handling of samples	7
	A biobank has controlled temperatures	3
	A biobank has freezers and different storage equipment	4
	A biobank is a custodian of samples	9
	Animal and plant collections can be used to prevent extinction of the species and also for genetic engineering and investigation purposes	10

In answering the first objective of the study, participants were asked to detail what they knew about biobanking. Several participants (70.6%) associated biobanking to the storage of samples for future use and research purposes. 82.4% of the participants also linked a biobank to a facility that deals with handling of samples and has different storage equipment and controlled temperature conditions. The following sub-themes emerged as discussed below.

What they know about bio banking

In the interview, participants discussed popular subjects and descriptions of biobanks. This may be directly related to their field of work. The majority of the participants knew biobanking as field of science or a process of preserving samples as expressed in the excerpts below.

“To me biobanking is the process by which biological specimens or specimens that have been collected from living organisms are preserved for future use in things like research so usually these are in most cases we cryopreserve”. **Male laboratory staff.**

“Biobanking to me is the field of science that deals with collection, processing and storage of biospecimens and their associated data for research use”. **Female biobank staff.**

One participant showed concern about storing all samples in a biobank and mentioned split storage as a process used in biobanking as a backup measure for safety of samples.

*“ When we are going to store our samples in the biobank, we also keep a reserve for ourselves, kind of like split storage. So, we do the split, we give half to the biobank and the rest is kept in our custody. So not to put all eggs in one basket and just in case things go wrong we have a backup and we wouldn’t want to commit everything to them or if we would do that those will be two biobanks. **Male laboratory staff.***

Description of a biobank

Table 4 shows the different descriptions of a biobank stated by the participants.

Table 4

A biobank is	Occupation
I personally I consider a biobank a body or an organization that deals with the storage of biological specimens for future use in research or research related.	Laboratory staff
I know it’s an organised place where biological samples are stored in an orderly manner and there are rules and regulations on storage, retrieval and labelling and access of these substances. A place where you store biological samples or substances for a long time in a safe secure environment.	Laboratory staff
A biobank is about sample storage for research purposes.	Sample transporter
It is a facility that collects, processes, catalogues, stores and retrieves biological samples for biological and medical research.	Biobank staff
A collection of samples with their associated data.	Biobank staff
A biobank is a place where biological samples collected from patient’s/study participant are kept in properly controlled temperature conditions.	Biobank staff
Can I say it’s like any facility that is set up that has qualified staff that does things like storage of samples? It’s like an institute that is set up maybe to handle samples let’s say like at country level we have like Uganda lab something MRC.	Sample transporter
I would describe it as a place with freezers for storage of samples	Laboratory staff
It’s a place established with desirable conditions for storage of live	Laboratory staff

samples either human or animal samples.	
A biorepository to me would be like a collection centre of samples that are going to be tested as required by time that is could be processed at a later time or could be as going to be processed at an early stage.	Sample transporter
So, a biobank I understand is a place where important biological material is stored for current use and use in the future.	Sample collector
Place to do with storage, with fridges, different temperatures.	Sample collector
I think it's a facility with different storage equipment specifically for processing samples and storing them.	Laboratory staff
In my opinion it's just a room with freezers and in these freezers is where samples are kept.	Laboratory staff
A biobank in my knowledge is I think a place where you keep samples for long time storage and for future use. Umm people use many different methods, some use liquid nitrogen others use deep freezers which go to -80°C, and yeah depends on the capacity of the organization but yeah for long time storage preferably -80°C.	Laboratory staff
I think a biobank is a facility that handles storage samples that are needed for research, any human samples that are needed for research purposes.	Laboratory staff

When asked if they consider a biobank a custodian of samples, some of the participants described a biobank as a custodian of samples and not necessarily the owner of the samples they store.

‘‘A biorepository is a custodian of samples just like you see a bank where you take money for storage, the bank isn’t necessarily the owner of the money, just a custodian’’.

Male Laboratory staff.

‘‘I think it’s just a custodian because if you say they own the samples that means they have the right to do what they want but they have protocols but I think they are just custodian. Like I told you it could be at the regionals level, very many organizations can bring samples to that institution for storage. For example, in MRC we do collaborative studies and these studies are in other institutions, these institutions don’t have like well lab set ups so they store their samples with MRC. So, MRC is a custodian. So I can say a biobank in simple terms could be like a custodian for regional

samples but they don't own these samples. Like I told you they are for research purposes, students need them...you know very many people need these samples. We could need development of vaccines so we could need these samples for the development of these vaccines. So, in my view it wouldn't be right to say that they own these samples I would say they are custodians''. **Male laboratory staff**.

Availability of biobanks in Uganda

Table 5 shows the list of biobanks in Uganda known by the study participants.

Table 5

Mentioned biobanks in Uganda	Sample collector	Sample transporter	Laboratory staff	Biobank staff	Total
MRC biobank	1	2	7	1	11
UVRI biobank	2		3		5
Ministry of Agriculture biobank		2	1		3
Makerere University biobank			1		1
The Integrated biorepository of H3Africa Uganda			1	3	4
Anatomy lab in Makerere University				1	1
Herbarium in Makerere University				1	1
Uganda National Health laboratories biorepository				2	2
The Zoo: UWEC				1	1
National animal breeding centre			2	3	5
Namulonge breeding centre				1	1
CPHL biobank		1			1
Cancer research institute Mulago			1		1
Fisheries			1		

Table 5: shows the number of participants in each occupation group that mentioned a particular biobank in Uganda and the total number of times that biobank was mentioned.

The biorepository owned by MRC/UVRI & LSHTM Uganda Research Institute was mentioned by most of the participants (64.7%) when asked about the biobanks they knew in Uganda.

One participant who described a biobank as

''a place where you keep samples for long time storage and for future use. Umm people use many different methods, some use liquid nitrogen others use deep freezers which go to -80°C, and yeah depends on the capacity of the organization but yeah for long time storage preferably -80°C''

was against the idea of thinking and saying that Uganda actually has biobanks. He said;

‘‘There is no set place or institution whose role is to do the work of biobanking, it’s usually the institutions that are carrying out the research and sometimes hospitals. They designate a place where they can store their samples but we don’t have an institution or body set apart to do the job of biobanking’’. **Male laboratory staff.**

Thoughts about animal and plant samples

Several of the participants supported the collection and storage of plant and animal specimens. Some felt that such samples can be used for research in terms of genetic engineering but also investigating diseases that can be found in both animals and humans.

‘‘Yes, it’s very worthy because I happened to inquire why they were storing and the key reason was they were preserving different traits and genes because they wanted to shift from the indigenous breeds to exotic breeds so they wanted to venture so much into genetically modified breeds. So, the major reason that they established that was specifically to keep the indigenous traits so that in future in case of any problems with the genetically modified breeds they would go back to the indigenous breeds’’. **Male laboratory staff**

‘‘Of course, because we do research and some of the diseases, we research about are cross cutting, they go into the animals as well like the chimps, the primates, and whatever so if there’s chance to store some of their samples to be used in the research that involves humans, it makes sense’’. **Male laboratory staff**

Other participants supported it because such samples can be stored to avoid extinction of particular species of animals, and even plants.

‘‘I had actually never thought of it but now that you’ve brought it up I think it’s worth storing plant and animal collections because I think of the pollution going on nowadays some of these things will be extinct in the future. But then I feel that for plant and animal repository would be more with the agricultural section and not with the one that deals with humans’’. **Female laboratory staff**

‘‘All collections are worth and relevant for the future of research. Plants and animal collections help guide the environmentalists on evolving trends of plant and animal species and help direct research to avoid extinction and improve better breeds’’. **Female biobank staff**

The benefits gained from storing animal and plant samples did not stop one of the participants to emphasize the ethical considerations that have to be followed.

*‘I think there’s no problem with that provided the ethical committee approves and there’s a reason why. Maybe other samples are collected to try other drugs and develop things because before drugs are tested on people they are tested on animals so I think it’s okay provided the rights of those animals are not violated’’. **Male sample collector.***

While many linked these sample collections to benefiting humans through different research innovations, an important aspect was highlighted about ensuring harmonious interactions between humans and the other aspects of the eco system.

*‘There is a chain of interaction between humans and all those others in the eco system. I strongly believe that to really find a way of getting a better health, we have to know what is happening away from the human. We have to do something on them to try to see whether we are living harmoniously with the other aspects of the eco system, and those are plants, animals, even pathogens’’. **Male sample collector***

Theme 2: Perceptions towards biobanking

Table 6 shows a summary of the main topics that emerged from theme 2 and the number of participants that thought that way.

Table 6

Theme	Topics	Number of respondents
Perceptions towards biobanking	More biobanks are needed in Uganda	6
	Willing to donate samples	13
	Supported shipping samples out of Uganda	9
	Supported donation and use of samples from the deceased	11
	Ethical considerations should always be observed in research	11
	Biobanking is not a priority in Uganda	1
	Ugandans are unwilling to donate samples	1
	Irrelevant storage of some samples	1

	Some research activities are unsafe and risky	1
	Biobanks are relevant for future traceability	2
	Biobanks ensure proper sample storage	5
	Biobanks support research activities	12
	Biobanks save time	3

To answer the second objective of the study, participants were asked about their perceptions towards biobanking. Participants felt that more biobanks were needed in Uganda. They were also willing to donate samples and the majority of them supported shipping of samples out of Uganda. The following sub-themes emerged as discussed below.

How they feel when human samples are collected and stored

Generally, the respondents did not have a problem with human samples being collected and stored for research purposes, however, some of them felt that ethical considerations should always be at the front line during any research activities.

*“Okay collecting samples, the way it’s done is, it’s done when a study is going on and they talk to participants and they agree to participate. Then their blood is taken for those who require blood samples and other samples. Now that should remain the only way through which samples are taken, because you can’t just be taking samples for which you’ve taken when someone is sick and then store it for future use. That would really not be correct because the ethics that is there that guides the research, that’s really what we adhere to”. **Male laboratory staff***

“I do transport samples but I also observe the process of collecting samples by study nurses. In other words, in research, ethics must be observed. Before you take my samples, give me a detailed reason why you’re taking them. I am working on a study about fore skin samples and we also take off blood samples and swabs. So now this is what I get from these participants when we ask them how they feel when somebody takes their sample...they say that they don’t feel so bad because “I know it’s going for research purposes but the main important thing is that they tell me the reason they are taking my sample”. So, we need detailed consenting. We have to tell them “can I take your blood, are you comfortable that I take your blood sample or do you want me to take your sample, do you want me to store your sample”? You have to tell them where you’re taking the sample, how it will be destroyed...you have to tell them that after 10

years we shall discard and even the way you're going to discard. You know working in the African setting, we have those cultural things so people are scared that if you just throw their sample just like that it could be used for ritual purposes. So, I have been asking these boys "how will you feel if I take your foreskin"?... then they tell me "I feel ok if a doctor is taking my sample but if it is another person and I don't know his experience am not sure if he is going to use my sample for ritual purposes. So, we have to consent them and give them this information so that they know where their sample is going. They have their rights to know what we did with their samples, so after taking their sample you have to bring back this information to these people and tell them what was found after the study. Because you told them that you would come back so it's their right to know at any point, at any state in the trial or research". **Male sample transporter.**

Competency of biobank staff and personnel handling samples seemed to be a factor that would impact research.

"I think the staff or personnel that are involved in that process, for example, the biobank staff need to get the proper training and they should be tested and proven to be competent to handle those samples. The reason I say this, different samples are handled differently and there are some that are more precious than the others. If you make just a slight mistake you may compromise those samples. For example, the PBMCs and Plasma. Plasmas can still be used even after leaving them at room temperature for some time. You can use them; you can freeze them back which will not be the case for PBMCs that are single use. Once you thaw them, you can't refreeze, so if the personnel are not really competent, they may handle the PBMC's in the way they handle plasmas and, in the future, if you want to refer to these samples you will find that they are not viable". **Male laboratory staff.**

Some participants in this study supported collection and storage of human samples and felt good and proud about being involved in some research activities.

"Sometimes I feel proud that am the one taking this sample that's going to be studied and is going to bring a new drug that will help my population. So sometimes I feel proud that I also took part in this study that is going to help people for example imagine time is going to come when our country is free of HIV. I will also brag telling my grandchildren or children that I was among those people that did that study that

developed a PEP drug in Uganda, so I don't feel bad. I feel so proud...in fact I even love what I am doing". **Male sample transporter.**

"As an individual I feel positive about it because with the line of research because we still need to discover new things about the human species. We still need to discover new medication. When the sample is collected, research is done on it & then it's stored. My first thing in mind is we shall retrieve that sample again in the future for further research which will be good for us". **Male laboratory staff.**

However, some participants found some research activities risky and also felt that some samples should not be stored because it would seem like a waste of space and money.

"Sometimes there are things which I think I don't understand better for instance when we look at different vaccines being tried out. So, I just wonder how they deal with that because they are testing a vaccine whether its potency is high or low...but they are using humans and the risk. For example, the HIV vaccine, I imagine sometimes if the participants are really asked to protect themselves because it would compromise the study. So sometimes those are the only fields where by I get confused but obviously it is research so such things are involved". **Male laboratory staff.**

"Ok sometimes there are samples that are collected and I ask myself as to why it's being collected because sometimes in my opinion, I feel it's irrelevant. Like COVID 19 samples, if you're storing negative samples...and you know like in Uganda negative samples are many, I feel like it's irrelevant and think it's just taking up space and you're going to just discard. Why not test them and tell the person that they are negative and move on. I feel like sometimes we should just collect samples for a particular purpose.... know what you want to do with the samples and collect for that particular purpose". **Female laboratory staff.**

One of the participants felt that biobanking is not a priority in Uganda.

"I think what I would ask would be, looking at the state in which we are here in Uganda, unlike outside there where you can keep samples for hundreds of years, is that do we see ourselves/ is it something coming from us Ugandans to have this section strengthened or is it something being pushed from outside? Because we seem not to have the resources to put into that. We look at it as secondary, I'm talking like this because our immediate issue is so basic, that we need to deal with. So, look at biobanking as something for those who have reached somewhere, who have achieved

*something. So, for us to get it, its maybe researchers from outside to fund it, sustain it and make the request for it, because for us, it's like we haven't reached the point of being able to dedicate resources into biobanking so yeah. If you cannot sponsor your own biobank, if it's the foreigner sponsoring the employees, they are still going to take our samples so its deception to say in Uganda we have a biobank. It's actually those people's biobanks operating in Uganda under Ugandan institutes. We have primary issues as a country that we look at and think yeah, that is the one we should deal with, and keeping samples and spending money on keeping samples right now looks like a secondary or even a tertiary thing. So, in a long time it's going to be funded by outside researchers and on a national level even if we put an institute for handling biobanks, they are going to be looking for money from outside to operationalize it because as a country we have topical issues to handle than collecting and keeping samples". **Male laboratory staff.***

Lastly, one participant's response was centred on the unwillingness of Ugandans to donate samples.

*"Many individuals do not favour the donation of blood samples for future research. Also, some Ugandans are hesitant to have their samples donated for genetic research or exported out of Uganda to Europeans and Americans". **Male biobank staff.***

Relevance of biobanks

Table 7 shows the reasons provided by the respondents about the relevance of biobanks.

Table 7

Relevance of biobanks	Occupation
<p>When I look at biobanking it's a system that is held by an organization or a body but in an organized way, where by you could wish to refer to a specific sample that was collected at a certain point in time. It is so crucial to the investigations that you're making or the research at that time point. Ummm it will be a way easier to trace those samples if there is somebody that has been handling them in a systematic way. And even to ensure proper storage conditions.</p>	<p>Laboratory staff</p>

<p>Yes, it's relevant, imagine looking through a freezer looking for a specific sample or in twenty and there's no order for that! So, it's nearly impossible without having an organised system. Yes it's relevant because if you can't store and access things in an orderly fashion then you'll lose a lot of time; patient time, research time and also you can't keep anything for the future because there's studies that run for 10-20 years and if you lose the samples then there's no sense in collecting them in the first place.</p>	<p>Laboratory staff</p>
<p>Biobanking is relevant for sample storage.</p>	<p>Sample transporter</p>
<p>Absolutely, biobanking is relevant. It is relevant because future studies and innovations in terms of drug discoveries and medical management can only rely on banked samples.</p>	<p>Biobank staff</p>
<p>Yes it is so relevant. It gives the researchers the opportunity to use available samples rather than collecting samples every time there is need to answer a particular research question.</p>	<p>Biobank staff</p>
<p>Without a biobank, you may not be able to acquire a good sample for your research.</p>	<p>Biobank staff</p>
<p>Like I told you they are for research purposes, students need them...you know very many people need these samples. We could need development of vaccines so we could need these samples for the development of these vaccines. One, we are in a growing world. Technology is growing so we need these samples to develop anything. If we want to modify anything for example the plant samples. When we want to have good genes of something we need samples to culture them so it's very relevant to keep a sample even if the plant wasn't all that so strong. If you merge it with something strong you can get good breeds so storage of these samples for a long period of time is really relevant. Also right now species are getting extinct so if we don't have any stored samples then that's it for that. For example the sperm samples, if we don't have the sperm samples of a specific type of animal that is almost extinct... for example right now we need to get the lion's samples so that in future if they are trying to extinct atleast we have the sperm. Then also when it comes to human diseases, like</p>	<p>Sample transporter</p>

<p>COVID-19 right now it's very relevant to store collected samples. So in future when something comes up we study backwards on how things came up. Biobanking is also very relevant for study purposes, for development of any drug, development of any vaccine and tracking of diseases.</p>	
<p>Because of storing samples that will be useful for future purposes.</p>	<p>Laboratory staff</p>
<p>Yes 100%, biobanking is relevant. Science is still very broad and we still have a lot of things that we haven't discovered about human beings so with the samples we need to handle these samples with a lot of care for future purposes because it could be a little bit hard for us to get a certain sample from a certain quality of people that we need so if at all we have got the right participants then it will serve us justice to make sure that these samples are well stored just incase we need them for future purposes.</p>	<p>Laboratory staff</p>
<p>I think it's relevant and very important. Because instead of calling back the client all the time to come you plead and what not... you can store these samples with consent from the client for further research so it reduces the costs, the time and the inconvenience of the client being pricked all the time.</p>	<p>Sample collector</p>
<p>It's relevant because at a later stage you might want to find out something and then relating the previous occurrences to the new occurrences so if there are no samples or biorepository then you'd have nothing to go back to in terms of relating the occurrences.</p>	<p>Sample transporter</p>

<p>It is relevant first of all because in biobanking there are guidelines followed which emphasize proper storage of samples so that they can be used in the future or later on even if its tomorrow. So it's important to have a biobank because we are going to have these samples safely stored for future use.</p>	<p>Sample collector</p>
<p>It is relevant if you're planning to use the samples in future.</p>	<p>Sample collector</p>
<p>Because I feel like when samples are banked for future use, for instance in the research setting that's where I've found the biobank more important and I've learnt that it should be extended to like hospitals set ups. In a biobank different samples are stored and later on when different researchers need samples it helps that if samples were stored in real time and perfectly, they don't need to trace participants for a given study. They can just use the same samples and if a given researcher looked at different analytes in a given cohort, it is much easier for another researcher to use the same cohort where a given paper was established to use the same sample and get better results rather than tracing the cohort. I have been in a hospital setup and have seen some patients with rare cases and their samples should be termed as "treasury samples" because it is on a rare occasion that you can get such participants. So, in my opinion if such samples are stored it is easier for a researcher to come and follow up. What I have seen was the hookworm in a stool sample at " Our lady of Consolata Kisubi hospital"... they stored it for study purposes for interns.</p>	<p>Laboratory staff</p>
<p>I think they are because these samples are kept and if someone would like to carry on testing in the future, I think it would be good. They are important for researchers.</p>	<p>Laboratory staff</p>

<p>I think it's very important because, samples as you know are very expensive to get and yet there are many things that are not yet known about medical situations and sicknesses and all these other things. So a lot of research still needs to be done. So if you have stored samples you have the opportunity to even go retrospectively and test them or find out things that happened many years ago which people didn't have solutions for and also for study purposes, for training purposes. Not every time you're going to train someone you're going to bleed someone but you can also get a sample and use it for demonstration and training people so it's very important aspect of science.</p>	<p>Laboratory staff</p>
<p>I think it's important for future studies for example if you want to fall back on investigations- forensic investigations, future studies, in case you want to work on your samples not on the real time you can always fall back if you've stored the samples and they are in good condition, and also for the normal storage of our samples.</p>	<p>Laboratory staff</p>

Some participants (35.3%) felt that Uganda needed to have more biobanks, when asked.

"If possible...if there's some money to avail others then good... because I think there's some samples discarded because of the space so they can't be accommodated yet they would be viable for future studies". Female sample collector.

"From my experience we really need more because I have seen how samples are handled in a hospital but sometimes even when different labs want to keep some samples like for instance HIV positive and negative samples to pull them and come up with inhouse quality controls... sometimes they are overwhelmed for some of those samples and they have to discard them. Yet sometimes they need to keep different samples for their in-house quality control". Male laboratory staff.

Participation in sample donation

The majority of the participants (76.5%) were willing to donate samples. However, some were not comfortable with some sample types.

"I feel ok when I donate blood, urine, saliva, nails and hair samples but I am not comfortable with the faecal samples. I imagine how the medical workers feel when they are working on it because of the scent. I would be ok giving it but if you're not going to

be the one working on it or if it's maybe even someone I haven't seen. A sample I can never give is lumbar puncture". **Male sample transporter.**

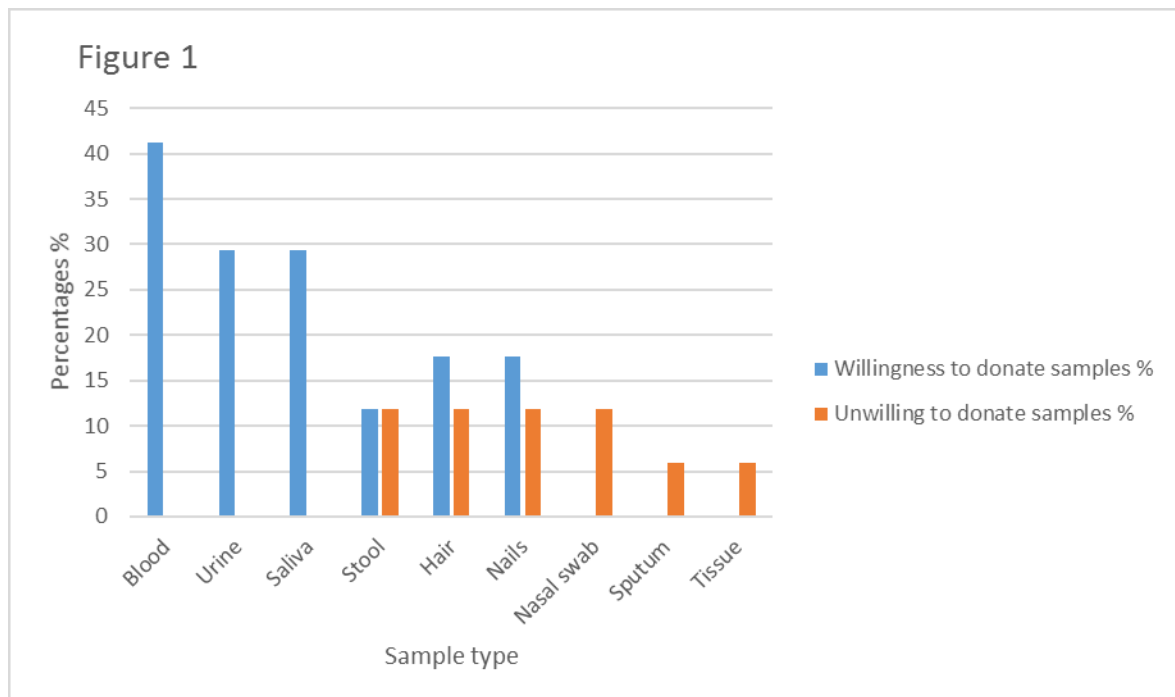
"I rather they collect blood or maybe saliva. But then when it comes to maybe like sputum or stool, I am uncomfortable with that". **Female laboratory staff**

A few of the participants were strongly against the donation of hair and nail samples.

"For nails, hair.... I have this perception 'where are you taking my nails'". **Female laboratory staff.**

"I would not be ok with donating any sample type. I am okay with blood and maybe urine. I would not donate hair, tissue or even nails. I would donate easier samples to collect". **Male laboratory staff.**

Figure 1 shows the sample types and the percentages of respondents that were willing and unwilling to donate those particular samples.



Blood (41.2%), urine (29.4%) and saliva (29.4%) were the most preferred samples for donation by the respondents. A few were willing to donate hair (17.6%), nails (17.6%) and stool (11.8%). Those unwilling to donate were; stool (11.8%), hair (11.8%), nails (11.8%), nasal swabs (11.8%), sputum (5.9%) and tissue (5.9%).

Some participants were not comfortable with the sample volumes.

“I was about to but I did not because the volume of sample they needed was abit huge for me. In the study they needed 60mls of blood from the participants so I was like ‘no’. **Male laboratory staff.**

“Taking a lot of blood which all of it you’re not going to use and you leave me dizzy”. **Male laboratory staff.**

Sample collection procedures seemed to also affect the decision one would have to make to donate their samples.

“I can donate any sample type as long as it’s convenient because there are certain sample types that are not friendly in terms of collection for example a nasal swab which is irritating. I wouldn’t participate in a study that requires a nasal swab.... maybe if I am sick.” **Male laboratory staff.**

“Yes, I would as long as it’s not intensive. I’d donate blood, urine, saliva as long as it’s not those deep-down swabs”. **Male laboratory staff.**

Fear for finding out their health status was also another factor that seemed to contribute to whether one would donate or not.

“To be frank I would donate because I even wanted to participate in a study that was, I think validating an immunoassay for covid-19 but obviously for given reasons I felt I was scared to go participant because I was wondering what if my sample is positive and all of a sudden, things would turn against me. But that reason is particularly to covid-19. But participating in a study is very easy and open. For as long as confidentiality is obeyed except for covid which I know would be challenging since it is contagious”. **Male laboratory staff.**

When asked about the donation and use of samples from the deceased, 64.7% were very supportive of it if consent is given.

“If the person who died was healthy and if the family of that person is ok with it because some have the perception that someone can’t die unwholly. They don’t want to bury someone who does not have every organ in their body. They want the person to go whole”. **Female laboratory staff.**

“In my opinion it would only help if the donors did consent to it and it would really help given the organs are used appropriately. Because it would not make sense if a donor

donated their organs maybe at no cost and these organs are sold at a very high cost or not a subsidized one because obviously no one will give it to you at no price because of processing and preparing it but at least at a subsidized price it would make sense”.

Male laboratory staff.

5.9% were against use of samples from the deceased.

“The deceased don’t give consent so sometimes taking their organs even with their relatives consent, is not what maybe they would have desired to do”. ***Female biobank staff.***

Concerns they have about the collection and use of samples for research

A list of the concerns raised by the respondents is shown in Table 8.

Table 8

Concerns they have about the collection and use of samples for research	Number of respondents
Stringent laws	1
Collecting huge sample volumes	3
Having less time for counselling and consenting	1
Use of samples for a different purpose other than the consented purpose	4
Unpredicted and unpleasant side effects incase of clinical trials	1
Participants not understanding research	1
Shipping samples out of Uganda	1
Ethical and consent concerns	4
The future of my sample when new research questions emerge	1
Communication of results	1
Collecting samples frequently	3
Unqualified sample collectors	1
Sample discard by the laboratory staff due to insufficient sample volumes collected	1
Painful & uncomfortable sample collection procedures	1
PI's just collecting and shipping samples out of the country	1
Misuse of samples	1

Some of the respondents' quotes are presented below;

‘‘My concern is in this; what I have seen over time is that many other sponsors bring a study, conduct it, after the study they collect the samples and take it. You know many of the sponsors come from out, because they seem to have more money there, so they finish their study and take the samples out there and they use it for other things which is not what the study was meant for. So in other words the place becomes an avenue for them to get blood from people and go and use it for other things out there because probably for them it's harder to get such samples so they use this place, like mining the samples and transporting it outside. So that one I feel bad about it. Most of the samples are transported outside so what they use them for out there we have no control over, we don't understand how they use it. So, they are exploiting, using this place as a mine’’.

Male laboratory staff. Exploitation

‘‘Now that's where I am having a major problem because that means the participants that volunteered to take part in the study do not get direct benefit much as yes the research is beneficial to the entire world. So, the researcher-participant communication should be 100%? Yes. Because there are studies that get very good results which could be beneficial to the participant but unfortunately it is just research’’. **Male laboratory staff. PI's just collecting & shipping out of the country**

The respondents were also asked what concerns they would have incase they were to be participants in a study that involved sample collections.

‘‘The future of my sample when new research questions emerge, consenting broadly is also questionable’’. **Female biobank staff.**

‘‘Shipping of my samples out of Uganda’’. **Female biobank staff.**

‘‘If I were a participant, I would be concerned about my samples being used for a different purpose other than the consented purpose. I would also be worried about unpredicted and unpleasant side effects incase of clinical trials’’. **Male biobank staff.**

Challenges of biobanking in Uganda

Like any other profession, biobanking too has challenges. Some of the challenges faced by the respondents were about the unpredictable weather disrupting transportation of samples, finding recipient laboratories closed and delayed sample delivery.

*‘‘One of them is the weather. Sometimes it’s raining and you have to transport these samples to the lab. If it’s one-hour transportation it’s supposed to be in one hour. By the way I have even had an accident before. The good thing is that I was just going to collect the sample. I haven’t faced any risks apart from the accident that I had but am always protected so I use PPE’’. **Male sample transporter.***

*‘‘And then sometimes the labs are closed at lunch time and I have to wait for the lab person to come and take the sample. If I come late, I have to answer but also the lab person has to answer. I always call when am setting off’’. **Male sample transporter.***

*‘‘Some samples maybe needed in a particular time of transportation and our transport network may not be favourable like incase of traffic jam, road conditions and even the time of departure’’. **Male sample transporter.***

Concerns received from research participants or the public relating to collection and use of human samples for research

The respondents reported a range of concerns they have received from research participants and the public. The main concern expressed was that the participants were uncertain about what their samples would be used for and were worried that they might be misused.

*‘‘They also have concerns about how their samples are going to be used’’. **Male biobank staff.***

*‘‘So, I have been asking these boys ‘‘how will you feel if I take your foreskin’’?... then they tell me ‘‘I feel ok if a doctor is taking my sample but if it is another person and I don’t know his experience am not sure if he is going to use my sample for ritual purposes you’’. **Male sample transporter.***

Uncertainty about where their samples would be stored was also expressed by research participants.

*‘‘Some of the research participants ask ‘after collecting the samples, where are they kept?’’. **Male biobank staff.***

Some research participants, even after being given the full information about a particular study, have still shown mistrust in the research that would be carried out on their samples.

*‘Then there can be a challenge of mistrust and they say ‘these people might lie; they will do other things with my blood and the rest’. Even after explaining to them some say no’’. **Male sample collector.***

They believed that some researchers collect samples for personal financial gain.

*‘Sometimes they think we are benefiting more than we are explaining because when we take off these samples, they usually think sometimes we sell them out. Other times they think we are having our own agenda that is not what is explained’’. **Male sample collector.***

*‘Some participants think research is all about business and researchers are just getting money from their blood’’. **Male sample transporter.***

*‘I think the most frequent is that they think that the blood that they provide for this study or for this test is being sold outside to other researchers there and the researchers are using their blood and they don’t know what they are doing there yet the blood was taken for a different study so they are quite concerned and they think all that is kept here is used for the purpose of money. Or is going to be traded in some time to come. It’s something that has been going on for a while, the participants are invited to come into where the samples are and they are reassured, so this has been not just once but for a couple of years. It’s been resurfacing again’’. **Male laboratory staff.***

Additionally, it was found that during the respondents’ interactions with some research participants, a number of them were not comfortable with the sample types, sample volumes and frequency of some sample collections.

*‘Another thing is people are not comfortable with all samples like stool samples because they really see it as unclean’’. **Male sample collector.***

*‘Participants also complain about too much blood being drawn from them’’. **Male biobank staff.***

*Yes, I have received concerns. Most of them be like “naye basawo (but doctors) you over collect the blood but where do you take itI gave you the last time, yes you said you would store but do you need all that and are you going to use it all, or you’re just collecting and wasting my time and later discard it’’. **Female laboratory staff.***

Delay in communication of results or not receiving their results at all was also one of their concerns.

‘I transport samples and what I get from these participants is that they don’t want to take part in research because when you take their samples some of you take long to communicate’. **Male sample transporter.**

‘Not receiving their results. There are those studies I’ve seen where they don’t receive their results at all’. **Female sample collector.**

One respondent reported that some participants would wish to take part in many studies but the exclusion criteria of these studies prevent them from participating. Others were not happy about being recognised for taking part in a research study.

‘I would not want to use the word blinded.... but it’s like these other motivators like the transport refund and the other stuff that is given to them, they will even wish to give more samples if they could. That kind of reimbursement and they would wish to be in as many research studies as possible though sometimes the criteria puts them out. Mostly those who have been involved before would wish to be even involved in more’. **Male laboratory staff.**

‘Some of them ask for certificates like maybe at the end of the study you call them maybe for some function since they’ve been involved in the research and given their samples, you inform them about the outcomes. They kind of like feel happy that they have contributed, that the samples that were picked from them and results have been published they feel like they have helped the nation at large’. **Male laboratory staff.**

Other factors affecting collection, storage and use of samples for research purposes

Respondents were asked to talk about factors that they thought affect collection, storage and use of samples for research purposes. The different factor codes that emerged from the subthemes are presented below.

Significance of the study

‘I think when I look at the significance and the rationale of the research and the objectives...depending on how the consent is I can choose to give them.... cause I also need to know what their objectives are. What are they aiming at?’. **Male laboratory staff.**

Person's current health

‘Yah and also my situation at that time. At times you are found when you are not really feeling fine’. **Male laboratory staff.**

Religion

‘There are some religions that don't allow people to donate samples. For example, I hear from the community that a Muslim person should only get circumcised in their settings and when they circumcise from these ends it's invalid. Then also there are religions that don't allow people to give samples. They don't want you to stay in hospital because Jesus will heal you...they don't take medicine because Jesus will heal you...they pray for you’. **Male sample transporter.**

‘They have affected the collection of samples to some extent because...am sorry to give this example but we have people called the Jehovah's Witness and they believe they aren't supposed shed blood and that's why they don't donate blood. They don't want their blood transfused into other people. If you meet a true Jehovah's Witness, they will tell you they don't believe in blood transfusion. So, I believe to an extent...maybe there is a certain parameter that we would have discovered in a certain group of people but because of their religious background we won't be able because they won't give consent’. **Male laboratory staff.**

‘In the perceptive of what I know, for instance when we look at Muslims, they do not believe in using condoms. So, if a study is looking at usage of condoms and protection from UTI's or STI's, they would obviously not accept to participate in such a study’. **Male laboratory staff.**

Culture

‘On a cultural level we have very many people who still believe in witchcraft. So, someone thinks ‘if I give my hair sample or if I give my urine sample, on top of research maybe they will do something else to it’, so they will fear. So, we need more sensitization’. **Male laboratory staff.**

‘Greatly it has affected collections of samples.... whereby there are some people who don't give out stool samples based of their culture.... they say our culture doesn't allow that for example here in Buganda you just can't take the Kabaka's (traditional ruler's) blood. That's a hindrance...for if you're supposed to collect the samples of the people in Mengo where even the Kabaka sleeps and then you're not

*supposed to see the Kabaka's blood....so how will you do it? So, you'll be hindered''. **Male sample transporter.***

Beliefs

*‘‘Some people believe when you take part in those studies and you take those drugs, they will make you impotent or barren, paralyzed or sick. And some of them speak out of evidence like ‘‘somebody's son was circumcised and is now taken years without healing’’. So, there are myths. **Male sample transporter.***

*‘‘The myths...I think as Africans we believe... ok we already know that the whites have made us their guinea lab so most Africans we believe when our blood is collected its somehow maybe taken to see... ok some people believe that that's why there is a rise in cancer...somehow the blood is diluted or people are going to create new diseases. Like how people believe that Covid19 has been created from the lab’’. **Female laboratory staff.***

Marriage

*‘‘And even sometimes spouses would like to know whatever the spouse does, and they would wish to have a discussion with them before they even get consented’’. **Male laboratory staff.***

Theme 3: Sample and sample data sharing

Table 9 shows a summary of the main topics that emerged from theme 3 and the number of participants that thought that way.

Table 9

Theme	Topics	Number of respondents
Sample and sample data sharing	In support of donation of organs from the deceased	11
	Against donation of organs from the deceased	1
	Researchers should communicate research outcomes to sample collectors, sample	10

	transporters, laboratory staff and biobank staff	
	Support sample and data sharing out of Uganda	9
	Against sample and data sharing out of Uganda	3

How do you feel about sample and sample data sharing with other researchers?

Several respondents supported sample and data sharing among researchers. Some felt it was okay only if data protection policies were followed.

‘‘It wouldn’t be a bad idea to share with other institutes for as long as the data protection policy is observed’’. Female biobank staff.

‘‘Okay, if MRC is to share any information with another biobank besides getting that consent from the involved parties, I also feel that if you’re sharing information with another biobank you should also specify which people should have access to the shared information at the other recipient institution. You’re basically dealing with people’s lives I presume. So, you can’t be going everywhere with ‘‘my blood’’ saying she has this then the other one shares’’. Female laboratory staff.

Some felt it was good to share sample and data to support more research studies and ensure reliable research results.

‘‘In like these outbreaks that come out, researchers from a particular institution might not be knowing what exactly to do in a given situation but, in another institution, there are others who might be knowing. So, sharing samples, I think, is good’’. Female laboratory staff.

‘‘I think it depends on the purpose for sharing but I think it’s also a fine idea because for instance if samples are analysed and then are stored and shared at a later date with a given other biorepository or lab and then the same samples are also analysed, it will give fairness in terms of reliability in results. You could even tell that maybe there are some discrepancies in a given batch of results. So, I think it’s for the good in terms of ensuring reliable results’’. Male laboratory staff.

Other respondents felt it was okay only if consent for sharing samples and data was attained.

‘I don’t feel good about it unless consent has been gotten from all the parties involved. I think if you’re to share, having got that consent, I think also the parties you’re to share to also matter not just everyone who is using that biobank or something’.

Female laboratory staff.

‘Yes I support it if there’s a memorandum of understanding then I have no problem with samples being shared because after taking off a sample from an individual, if the individual has allowed the sample to be used for further research then I think there’s no problem with sharing because it is through sharing where we compare people from different cultures, different regions and also to develop a widely acceptable vaccine or drug so we need to use different samples from different people’. **Male sample collector.**

Others felt that samples and data should be shared only if the samples are to be used for their intended purpose and if the recipient researchers are in the same line of research.

‘I think it’s okay for as long as there is mutual agreement between all involved parties and samples are used by their intended purpose’. **Female biobank staff.**

‘It is okay as long as they are in the same line of research’. **Male sample transporter.**

Majority of the respondents supported communication of research outcomes by researchers to sample collectors, sample transporters, laboratory staff and biobank staff.

‘Researchers should also communicate the outcomes sample collectors, sample transporters, laboratory staff and biobank staff. This motivates the participating staff. It also improves inclusivity and ultimately leads to system, process and procedural improvements of the institution’. **Male biobank staff.**

‘Yes, it’s very important for me to know the outcomes of a given study say. For instance, there was a study that was done trying to evaluate the stability of glucose concentrations in different vacutainers subjected to different conditions so the end result of that study was to determine the pre-analytical sample handling in different places. Where samples are subjected to different conditions before being handled. So, we realised there was stability in glucose samples that were immediately aliquoted and stored in very low temperature so that alone is enough for me. I would like to always know the outcomes of the study because it would also be of great importance for me to improve my skills in terms of pre-analytical sample handling and it will also enable me

to be more knowledgeable and give advice to other incoming studies pertaining the same kind of line''. **Male laboratory staff.**

''I feel like at the beginning of the study you go through all these trainings...they explain the proposal, the protocol so sometimes I wonder what happened/the outcome. It would also help you if you want to do further studies and research and be able to see the gap from other people's research. They put up their articles on the website but sometimes I don't see the articles of the studies whose samples I worked on and all they tell you is that the study is over''. **Female laboratory staff.**

However, a few felt it would be best for some information to remain between the researcher and participants only.

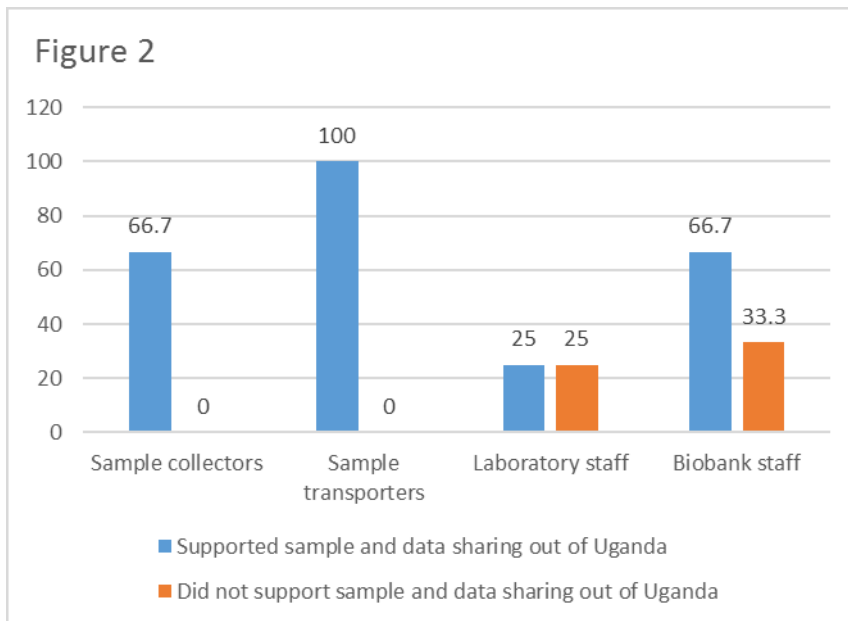
''Research is done as a team. So, the whole team should be informed on the way forward and keep informed. Though not all information is communicated to all. Some information remains confidential between researchers and participants''. **Male sample transporter.**

''For specific patient results, it's a No due to ethics privacy and confidentiality. But for overall research findings, it is a yes as it's a motivation to the employees for their efforts rendered during the study tenure and also general knowledge since research objectives address issues within our communities''. **Female biobank staff.**

Do you think they should share samples and sample data with only local researchers or even out of Uganda?

Regarding support of shipping samples and sharing sample data out of Uganda, 9 supported it and 3 did not support it (Figure 2). 2 out of 3 sample collectors supported it. All the transporters supported it. 2 out of 8 laboratory staff supported it and 2 out of 8 did not support it. 2 out of 3 biobank staff supported it and 1 did not support it.

Figure 2



Some respondents were in support of sharing samples out of Uganda because they believed it would support different research avenues and ensure validity of research results for samples tested in Uganda.

‘Disease does not restrict or isolate and say that ‘you are black, you are white.... you will not get this disease’. Okay some of them are environmental or related to some groups but most these diseases are not restricted to a certain group. You have your HIV which will be all over maybe some few strains. But diseases do not isolate. We are fighting a war to make sure we have a disease-free world and out there, there is the same disease that would affect Uganda although abit different in some aspects but still generally disease is out there. So, if there is some researcher out there willing to help out in overcoming a medical problem, I think it is very okay. Maybe the ethical aspect of it. The participant of the collected sample should be very informed about sharing or shipping of their samples’. **Male sample collector.**

‘I support it. Ofcourse the participant has to agree for it...I don’t have any say to that. It’s even better we share ideas and information now for example some studies some samples are taken and some are analysed from here and some are analysed from the UK. So, we share samples because we want to get valid data. For example, if you say that you’ve tested blood and it has been 100% let’s test in other countries to see the validity of your results than just relying on you so I think that it’s very good’. **Male sample transporter.**

However, some respondents were against shipping samples out of Uganda and were only okay with foreign researchers testing the samples from Uganda.

‘This is how I think it should be done, if they want to do a study on samples let’s say stored in MRC, they should come to MRC and say “MRC Uganda, this is our proposal, do you have the sample which we can use to carry out the study”? If we have the sample then let them come and do the study in collaboration with the people who are here. Not ask to send the sample without the people who are here. That one I do not agree with. In the end you see what they are doing is they are paying some money and they are taking the samples, it’s like they are buying the samples which is bad. The sample is taken to the other place and what is received here is some money. Of course, they won’t tell you that they’re buying, they’ve taken but that’s already some sort of trade. And that is what I’m against’. **Male laboratory staff.**

‘There is the thing of samples being shipped and tested abroad and it really doesn’t make sense. In my opinion samples should be tested from where they are collected because to some extent a participant in their consent forms are told by the PIs that they will share results with them which I don’t expect is done with the samples that are shipped. When samples are shipped it makes it extremely hard for them to be shipped back yet they are collected to support research within that particular country mostly. Abroad it can be done by sharing data so I think that’s where I find a bit of a challenge. They are shipped and not shipped back. But like I said I am giving you my opinion. To me the way I see things that’s how it has been although I have not interacted with people that have shipped samples but that’s how I see things’. **Male laboratory staff.**

‘I think that’s where that whole thing comes up of.... most Africans don’t want to share their samples because they know it’s the whites going to use them after all. Yes, I think it’s ok to share because Africa we have many diseases so it’s useful in the research but then I feel sharing of results might cause some kind of bias. You know when these guys are testing, they will compare the first results got to theirs incase they are not tallying. Sharing samples with those guys abroad...I don’t really like it a lot and I don’t feel strongly good about it. Maybe if they come and do their research from here, leave the samples here and the data...because it belongs to Uganda.... but not sending samples to their countries. I only agree to local researchers using samples here’. **Female laboratory staff.**

One respondent supported it only if the samples were to be shipped back.

‘If researchers can accept that if those samples are shipped, there are higher chances that they would be shipped back. Because if they are shipped and not brought back that means the local researchers will be affected because the reason as to why they were stored in the first place was to support research locally and maybe internationally’.

Male laboratory staff.

Some respondents put emphasis on ethical considerations before shipping samples out of Uganda.

‘To me I have no problem samples being shared or shipped to other countries as long as confidentiality is kept and considering the misuse of samples and the outcomes of results’. **Male sample transporter.**

‘I would agree sharing them out of Uganda. But in my opinion, I feel like if unless that is included in the consent form so that participants know that at a certain time the samples will be shipped and tested abroad. Because with this era of bioterrorism we can’t deny the fact that if samples are mishandled anything can happen and I think that’s why there are huge restrictions on samples that are shipped in from abroad’.

Male laboratory staff.

Sharing samples was also attributed to being dependent on the ownership of those samples.

‘But the major problem is ownership of the sample. For as long as there is a mutual understanding that incase another researcher in Uganda has interest in those sample they will be shipped back. And maybe also attaching maybe a given section whereby if samples are shipped for a certain test, they are specifically used for that test and no further tests are carried out’. **Male laboratory staff.**

‘So, I think that would depend, I would put it to the person who owns the samples. Remember we said the biobank is just a custodian, they don’t own so if the owner wishes to have these exposed to other countries, that will be fine but if they wish not to the, still retain the ownership, their decision will be like final’. **Male laboratory staff.**

One respondent did not like the fact that some PI’s just collect and ship out samples.

‘Now that’s where I am having a major problem because that means the participants that volunteered to take part in the study do not get direct benefit much as yes the research is beneficial to the entire world’. **Male laboratory staff.**

Opinion on the communication of research results from biobanked samples to participants

Generally, the respondents supported researcher-participant communication of results.

*‘‘Researchers should definitely share results to participants. Since biobanking is for the good of the public, why not share the research results’’? **Male biobank staff.***

*‘‘Participant’s engagement in their sample research outcome should be shared efficiently and in a way that all the participants understand the results’’. **Female biobank staff.***

However, a few felt that it was important for researchers to agree on the type of information to share with the research participants.

*‘‘I think it is important though certain information should be restricted to certain people. You would wish to inform the public about even the outcomes but still the information the PI knows is not the same information that the laboratory tech will know and it’s not the same information that the public should get to know so there is that kind of filtration of data. Know how much to give to them because you won’t express all the data of the project. So, you just filter and know which one to give to the public, the information to give to the collectors, transporters, laboratory staff or biobank staff’’. **Male laboratory staff.***

*‘‘It depends on the information shared at the beginning and the consent is signed. Both parties should agree on when and what to share’’. **Male sample transporter.***

A few also felt that not all research participants are always interested in knowing their research and the general research outcomes.

*‘‘What I can tell you is that most of our participants they are even not interested in your results. However much we promised to tell them, but then they are interested in the direct benefits they are going to get. They are more interested in that transport reimbursement, a few are really interested in taking part in the study’’. **Male sample transporter.***

*‘‘Some do, some don’t. Depending on the setting in Uganda. If you are dealing with people who are not really learned some don’t but when you get one who is learned, they would want to know’’. **Female sample collector.***

Theme 4: Recommendations to improve on Biobanking

Table 10 shows a summary of the main topics that emerged from theme 4 and the number of participants that thought that way.

Table 10

Theme	Topics	Number of respondents
Recommendations to improve biobanking in Uganda	Holding biobanking trainings	7
	Developing biobanking courses	3
	Sensitization and biobanking awareness	5
Recommendations to improve biobanking at MRC	Installation of the best system for sample management	2
	Expansion of the biobank infrastructure	8
	Charging researchers for sample storage	13

In Uganda

The recommendations for the improvement of biobanking in Uganda are presented below;
Establish Guidelines and a Biobank Monitoring body

‘I think the idea of setting guidelines. Like there can be an established body to follow up and see that those guidelines are implemented and then the accreditation of the different biobanks to ensure that they are accredited. I think that will generally improve biobanking’. **Male laboratory staff.**

Free Sample management systems

‘Make storage systems free like LIMS and Freezerworks...make these programs open source for people to use so that if you can just download a biobanking programme and you enrol it into your system then it will become cheaper’. **Male laboratory staff.**

Trainings

‘I think the staff or personnel that are involved in that process for example the biobank staff need to get the proper training and they should be tested and proven to be

competent to handle those samples. The reason I say this, different samples are handled differently and there are some that are more precious than the others. If you make just a slight mistake you may compromise those samples''. **Male laboratory staff.**

''Develop 2-3day training camps and short courses for research professionals that are in anyway involved in the biobanking chain (collection to storage)''. **Female biobank staff.**

Education

''Introduce a module on biobanking in all biological and science related courses at university. Introduce short courses and biobanking workshops''. **Female biobank staff.**

''Is there a course for biobanking? So, one of the strategies I would propose is let our Ministry of Education and Sports stream line or develop the course because it is something very important''. **Male sample transporter.**

''Maybe to educate people the usefulness of the biorepository because people think it's just storing samples but they don't know why, for what, what it could do to the country's research system. Like I said if maybe we just allow the internationals to come and do research here then I think it will increase the awareness''. **Female laboratory staff.**

Providing equipment and electricity stability

''Equipping these facilities with the necessary machines and the stability mostly of our electricity because these facilities use freezers so stability in power''. **Male sample collector.**

Collaborations

''Not to centralize this thing....it should be distributed to other centres. But there is a problem as the nation, I think they need to not only rely on UVRI or JCRC, but should let all these referral hospitals be encouraged to do research and store samples because we miss out on some vital information. **Male sample collector.**

''In my opinion it goes back to the laws. If we would have open laws or collaborations between major biobanks for instance if I use MRC biorepository as an example...if in a given region for those rare cases in different hospitals if they can allow participants or patients to consent, because in most times such cases are referred to Mulago hospital for further follow up. So, if there would be a collaboration or a given law.... if doctors

or clinicians come across those rare cases, they should inform a given biorepository, so that they collect more samples so that if there are researchers interested in such cases they can easily follow them up. They should come up with collaborations with different hospitals because every single day thousands of samples are discarded and also different PI's spend a lot of money recruiting participants yet it would be much easier''.
Male laboratory staff.

Sensitization & awareness of biobanking

*''A lot of sensitization needs to be done. As students, Universities need to begin informing students that there is something called biorepository and Biobanking. Because I myself I had never heard of that. I had never heard of biobanking and biorepositories. In fact, when I came here, I heard of the word ''biorepository'' and I was pronouncing it as ''biodepositories''. So, I didn't even know the pronunciation. So, a lot of sensitization needs to be done right from our Universities. **Male laboratory staff.***

*''Since biobanking is ''core science''...the knowledge of biobanking can be improved through radio presentations, media, interactive discussions among researchers, public address in an area where there is a process that needs to be done. I don't think the whole world will be so interested in biobanking, but to those people that have to participate in studies need to know about this and also researchers or groups that are directly responsible. And even the world at large may need to know because at the end of the day we don't want to have a whistle blower coming out to create hullabaloo because they do not know anything about it. So maybe everyone needs to know but, in a process, the first ones to know should be the contact people, the responsible people then everyone could know later''. **Male sample collector.***

*''I think teaching people about the importance then having forums where people can be exposed to what happens in the biobanking system because even us here we know it's just where samples are kept and we don't know anything because even the meetings which happen at compulsory some of them we're not involved even the ones we're involved it's practically different stuff. You don't get really exposed to know what other people are doing elsewhere''. **Female sample collector.***

Institutionalizing biobanks

''I think institutionalizing. It can do a great job in improving it because in that way you can set for it infrastructure, put up infrastructure to house the biobank

*section/department and be able to better monitor the temperature and environmental condition, set up good power and water system. Institutionalizing would also attract more money to improve the biobanking''. **Male laboratory staff.***

At MRC

The recommendations for the improvement of biobanking at MRC are presented below.

Staff appraisals

*'I think one of them would be to evaluate the number of staff that they have given the work that is present of expected to be''. **Male laboratory staff.***

Opening the institutional Biobank to the public.

*'I think opening it to the public would help it improve more because usually when you are working on something you own personally you feel you have more control to implement anything, any idea that you come up with because you know it is yours, no one else will have a say but when you open it to the public you know that you need to get feedback from all the other people around, I think you end up with a good system. So, opening up to the public will kind of improve the system a lot. Yah and if it is not there at least bodies like MRC or UVRI that have, can just upscale because at least they have the foundation. Other than just having something new... the trust wouldn't be there''. **Male laboratory staff.***

Installation of the best system for sample management

*'I think it would be about the electronic system that is used to store those samples for example Freezerworks. I think they need to first explore all the systems that are available to really source out the best. The reason am saying this is for example... at least for the experience we have with Freezer works, there are so many frequent upgrades and usually some of them have errors. I think that would not work for the general scale if this biobank was open to the entire public and the system keeps failing, all the time having upgrades. So, I think they should give it time and source out for the best that is available which is trustworthy''. **Male laboratory staff.***

'Maybe software. Is Freezerworks the best software because I think they should explore other software? Because there is a time, I used it during some study and the ID's were confused'. For the UVRI biorepository they should also explore another

*software because what they have now is not the best. Sometimes the system goes down so what you have achieved and not saved you would have to redo **Female laboratory staff.***

Human resource

*‘‘Hire more staff to reduce pressure on people who are not directly involved in biobanking.... if I can collect and hand over immediately to the repository and they handle whatever is involved with the storage totally, that would be good’’. **Male laboratory staff.***

*‘‘Generally, I have realised there is a lot of work to be done in biorepositories and in biobanking systems so much more personnel need to be involved because the work is really too much. For someone who has been to biorepositories you can tell. A lot of human resource is needed to cut down on the stress levels in terms of work. This opinion is for MRC and also biorepositories in Uganda’’. **Male laboratory staff.***

Full governance by the biobank staff.

*‘‘They should handle everything, shipments,.. Storage because some samples are not handled by the biorepository. That should make a streamline’’. **Male laboratory staff.***

Expansion of infrastructure

*‘‘MRC should definitely expand the biobank infrastructure. Being a centre of excellence, MRC conducts vast research which calls for advanced infrastructure and equipment’’. **Male biobank staff.***

*‘‘The growing number of research projects gives increasing numbers of samples and this should be a platform for looking into all aspects of the repository including staffing, equipment etc. This will also allow for visibility of available samples to other researchers outside the MRC’’. **Female biobank staff.***

*‘‘Buy new temperature monitors. Employ people who are going to work...people should work in shifts because we need these samples’’. **Male sample transporter.***

‘‘I don’t know how big it is. But research is still ongoing and there are a lot of research studies coming up so I really think if MRC started in 1989 or UVRI started in 1990’s or in the 20’s they can never have a similar biobank. Because I joined MRC in 2014 and new studies have been coming in and I have worked with around 10 studies which some have ended and others ongoing and others starting soon. We have a new study coming

*up so if the biobank is not big enough, we shall not be able to have a place to store these samples and we cannot store them in any other place that is not fitting the criteria for right storage. How do I come as researcher with a grant to MRC as a collaborator and find that I cannot store my samples with them for even just next month or next year's testing that I need to do? So they need to expand if they have not yet''. **Male sample collector.***

Trainings

*'MRC should train biobanking staff and also include biobanking staff at all levels of research projects''. **Male biobank staff.***

*'And to also give trainings to almost all MRC staff such that they can get to know what biorepository is and what it is all about. That is why I am telling you that if they tell people that if samples were to be needed at a lesser stage and we were to be testing a particular thing they are supposed to be kept under particular temperatures... because now I feel like this info is only kept to the people who are working within the biorepository''. **Male sample transporter.***

Improvement of MRC output

*'Develop a good biobank structure. Develop a virtue biobank with all samples well catalogued''. **Female biobank staff.***

*'For study purposes you should publish because the whole point of the study is to learn so publish the results so that other people learn but don't publish individual results but publish the outcome generally. Please go back and tell the participants the outcome of the study and do it in simple English and not use your medical terms''. **Male sample transporter.***

'They should make it more independent so that it can easily enlarge and at the same time the MRC biobank should start doing research that is connected to biobanking. For instance, one would look at ...obviously it's going to sound non-scientific...but we can look at different parameters like 'if a sample was collected and frozen, what would be the difference if its subjected to different freezers -80°C, -20°C and 2 to 8°C''? What would be the difference maybe for chemistry parameters or even one can just decide to look at haematological parameters. So the biobank should also do research and see how to support the testing team because if different studies or results can be generated showing that, for instance, if a sample to be tested for creatinine is collected and

immediately transferred to a -20 and put into a shipper then transported to the biobank into a -80 within a certain period of time, the results won't be so different. That means even the workload...instead of a lab being overwhelmed by testing thousands of samples they can store then test later''. **Male laboratory staff**.

Sensitization and awareness of biobanking

'Have general awareness training for biobanking education for the entire research community from PIs, clinicians, lab staff and participants. Community sensitisation is also paramount''. **Female biobank staff**.

'Maybe when we get to the organisation and the people who carry out the whole collection bit and you know maybe the studies we're dealing with collecting and storing. When they are training maybe with SOPs, they should actually give a section to the biobankers to maybe tell us what happens. I remember the first time we were trying to figure out where our sample storage is this is when I was bombarded with a full list of things to be filled in like all of us did not know about it... whether it existed or not. Now I'm imagining we had sent samples before doing all this because we don't know, we're not taken through this whole thing so you don't know what happens there. You just reach somewhere and you find a wall and you're like okay. Then on top of that okay you guys should be involved because when you are doing the whole study what you're going to face on the other side of the coin. Then they tell us we have to buy these equipment's for storage.. but I don't think that was planned on the study. I understand to be sustained you need support from other studies. Yes, you might actually blame them but they also don't know...not really blaming but also you might find as they are writing they also be like I want my samples stored but they also don't know what is happening at the storage. Sensitisation is needed. I don't know where the MRC biobank is. I think when I was joining they just took me to some particular places, the rest you actually don't know so ideally even now people are not oriented so how do you know where what is. I think it should be known (the biobank) because different people at some point will need their services''. **Female sample collector**.

'And biobanks need to market themselves, they are still on hideout yet they are very important''. **Female laboratory staff**.

Staff involvement

*‘‘Apart from the staff reading about the research outcomes on the MRC website, I feel like if there can always be a journal club or something of a kind where by its not specifically for just presenting journals that were found interesting online, but for studies to present their results to the people that were handling the samples so that they can get to know the outcomes and how they are beneficial. Other than people just handling studies when they don’t know what the studies are looking at, it does not make sense because it even compromises the sample handling. So, if one knows they are handling a validation study, then they will know how time and the protocol really makes sense’’. **Male laboratory staff.***

Collaborations

*‘‘Well, first is making collaborations with hospitals that are within regions in Uganda. That would mean that MRC would have to set up an independent biorepository specifically for biobanking and look forward to banking sample types other than what they are dealing with’’. **Male laboratory staff.***

*‘‘In my opinion I feel like the biorepository should work in synergy with the various different labs because samples sometimes are got from the lab and then taken to the repository. So I think the SOPs should be in synergy so that the lab understands that in their SOP if its analysis of a different sample it should either be analysed immediately if reagents are available or it should be stored in accordance to the repository guidelines or SOPs’’. **Male laboratory staff.***

Encourage more sample storage

*‘‘Maybe they should encourage more sample storage so that incase these outbreaks happen people should go out and take off the samples in storage’’. **Female laboratory staff.***

Documentation

‘‘I think probably the documentation procedure can be improved. Even in Uganda as well, because I think this study, I believe will be a basis for future studies, its findings. Yeah so documentation I believe is very important for the clinicians and the Biobanking people to know that umm, the time the samples arrived, the time they stored them, I feel it’s very important because if you’re like handling Chemistry plasma and you’re going to work on plasma on a later date all those things affect, every second affects, and urine.

So I feel documentation can improve and yeah basically that's it''. **Female laboratory staff.**

Respondents were asked how they felt about MRC biorepository charging researchers for sample storage. Majority supported it.

''If you reach a point when all the samples that are in the custody, the different projects carter for them and pay for their storage, so I think in that way it can be easier for even welcoming samples from elsewhere because they will have to fit the criteria and pay the amount for the storage. But this whole idea of storing all of them in bulk as MRC is costly''. **Male laboratory staff.**

''Yes, obviously because running those freezers and keeping the samples in that state is very expensive so they should charge. And the biorepositories should have core funding not only depending on projects because am looking at it at a point whereby if most projects are done and the projects remaining cannot sustain the repository that would call for people that need these samples of those projects that got done and never discarded them. Meaning the MRC bank would be losing out''. **Male laboratory staff.**

''To some extent, yes. Because these biorepositories need to keep in operation so for them to do so whoever is going to benefit from the biorepository, to me I think should be injecting in something, and not only researchers but even the government. Because if researchers do publish their findings, it benefits the entire population if it's positive so the government would atleast portion some money to make these biorepositories keep in operation''. **Female sample collector.**

''I support the charging. Because when storing this sample, you need to store it the right way at the right temperatures, you need to have a quality check and a good environment. So if these researchers or anyone using these samples is not paying for storage, then how will maintenance be done? Because if you are using a freezer and require your sample to be stored at maybe -80, you need a lot of electricity, gadgets that can manage to sustain that temperature, you need staff to make sure everything is maintained the right way, you need servicing, transport of required supplies etc. So a lot of things are in the back of the decision to charge, but if they are not well explained someone may think there is nothing much. If I personally who doesn't work there can think about them, how about someone who is sitting there and they know how important it is to store these samples in the right way. Because science can change because of poor storage''. **Male sample collector.**

However, a few felt that the biorepository should be lenient when charging for sample storage.

‘It’s a good idea however we should look at the person storing because sometimes we may bring these things but how are they going to help research. I know research there is no money so they have to be lenient with the cost. If I am going to store over 1000 samples for 10 years I should be charged not per month. It’s fine to charge for sustainability but also it shouldn’t be abrupt. Any study that is in transit shouldn’t be charged but any new upcoming study should be charged’. **Male sample transporter.**

‘I would partially support it but to a greater extent I wouldn’t. Because if I were the owner of a study, I would feel a little more pinched when am being charged for storing after I had paid for analysis of those samples. I think it should be done this way...they should evaluate the whole sum together with how much should be charged for storage for a given period of time and then the PI gets to know the amount of money at once. Let me put it simpler this way...if I have a child in school, maybe in primary or high school and am going to pay school fees. Then after paying fees when I reach the school, they tell me am supposed to pay for a text book, I would feel kind of hurt. But if I am told earlier and if everything is summed up within school fees then its fine’. **Male laboratory staff.**

4.0 DISCUSSION

This is not the first study to explore views of Ugandans on storage of samples and research carried out on stored samples (5). However, this is the first study in Uganda that has focused on exploring the views of specific groups of people that are involved in biobanking. The findings of this study are discussed below.

Knowledge about Biobanking

According to this study analysis, 70.6% of sample collectors, sample transporters, laboratory staff and biobank staff were able to associate biobanking with the storage of samples for future research purposes. The majority of respondents were aware of what biobanks do since 94.1% were able to describe a biobank. Approximately 41.2% in this study perceived a biobank as facility that deals with handling of samples, 23.5% considered it a place with freezers and different storage equipment and 17.6% thought of it as a place with controlled temperatures. Also, Nicole et al. (33) reported that 65% of health professionals considered a biobank as a facility that stores biospecimens. Although Europe is in the vanguard of biobanking, Gaskell and Gottweis (34) in 2010 found that two thirds of 32 European countries that were surveyed in the study had never heard of biobanks and less than 2% had searched for information about biobanking.

Further research studies (35, 36, and 37) have demonstrated a notable lack of knowledge about biobanking among health professionals. 56% of clinicians were completely unaware of the Declaration of Helsinki (38) and only 27% of healthcare students had heard of the word biobank (35). In Cote d'Ivoire, 47.3% and 43.4% of laboratory staff had never heard of the terms biocollection and biobank, respectively (39). Despite deficits in knowledge about biobanking, the majority of health professionals (82.9%) were willing to donate their own biospecimens to biobanks and 82.8% accepted to describe to patients the role of biobanks and persuade them to take part in biobanking (36). Igbe et al. (40) argued although only one person had heard of biobanking prior to the study, the majority of lay persons in Nigeria welcomed the idea of storing biological specimens for research.

Perceptions towards biobanking

Numerous publications address the perceptions of donors and society on biobanking, but the views of biobankers are hardly discussed (41). Many studies have cited perceptions of benefits and risks of biobanking as a critical factor in public attitudes towards biobanks (42). The Malaysian stakeholders in the Klang Valley that took part in this study (42) felt

that biobanks were definitely relevant. Similarly, Simon et al. (43) in 2011 reported that 84% of the residents in the catchment area of the biobank that was being developed at the University of Iowa thought biobanks would be valuable.

The majority (76.5%) of respondents in this study were willing to donate samples. They were willing to donate mostly blood (41.2%), urine (29.4%) and saliva (29.4%). Similarly, an assessment carried out in 2017 (35) showed that blood (82%), saliva/sputum (77%) and urine (70%) were the most preferred by the healthcare students that took part in that study. 11 out of 17 participants in this study supported the donation and use of samples from the deceased. Unlike in this study, the participants in a study by Merdard (35) were not in much support of donation of organs from deceased family members as only 25% supported it.

Interestingly, a respondent in this study felt that storage of some samples is irrelevant and a waste of space and money.

“Ok sometimes there are samples that are collected and I ask myself as to why it’s being collected because sometimes in my opinion, I feel it’s irrelevant. Like COVID 19 samples, if you’re storing negative samples...and you know like in Uganda negative samples are many, I feel like it’s irrelevant and think it’s just taking up space and you’re going to just discard. Why not test them and tell the person that they are negative and move on. I feel like sometimes we should just collect samples for a particular purpose.... know what you want to do with the samples and collect for that particular purpose”. **Female laboratory staff.**

In other studies, respondents were concerned about the benefits of biobank-based research. In a study by Luque et al. (20) assessing southwest Florida community members perceptions of biobanking, citing an example of cancer, one study participant said *“When we are talking about this research, and any human being ... to donate for research. To me, it should be more PERSONALIZED in the sense of some cancers affect some people, and the same circumstances don’t affect other people. So, in my opinion ... I kind of feel like the research is time wasted”* (20).

In this study, there were different concerns stated by the respondents regarding the collection and use of samples for research. Ethical and consent concerns were the most mentioned (23.5%). Domaradzki and Pawlikowski (5) also reported fear of linking respondent’s samples with their personal data. They perceived risks of participation in biobanking including the probability of using their specimens in research studies that are in

contradiction to their moral principles, and access to sensitive data by the government and employers. In another study, research professionals from Egypt and Morocco expressed concerns on the protection of privacy of research participants in clinical research, “but because we are well-educated, we understand what privacy is...But most of the community doesn’t think of privacy at all. It’s none of their concern, seriously.... They don’t know that there are laws...They don’t know their rights about privacy.... Do they know that doctors are sharing their information with other people”?” (44).

17.6% of respondents in this study expressed concerns about collection of huge sample volumes and 17.6% were concerned about some research projects requiring frequent sample collections. In a Gambian study by O’Neil et al. (45) in 2016, the risk of a finger-prick blood collection was perceived as potentially hazardous although the actual risk was non-existent. Study participants asserted that they were afraid of losing so much blood that they would require hospitalization due to blood deficiency, which would then necessitate buying someone else’s blood. The fear of donating blood has also been reported in other countries across sub Saharan Africa and has been linked to the fact that blood is viewed as a life force and its absence signifying immanent disease and decline in strength (46).

Respondents in this study have received different concerns for research participants. Some of the concerns they stated were about misuse of samples and researchers collecting samples for personal financial gain. In South Africa (18), researchers expressed concern on commercialization of biospecimens. They asserted that selling of samples should be banned. *“Human tissue is this untouchable Holy Grail that you can’t mess around with, you cannot abuse it, you cannot sell it, and you cannot make a profit out of it”* (18).

Trust towards biobanks positively corresponds with willingness to participate in biobanking and reduces perception of risks associated with biobank research (5). Higher willingness to donate biospecimens was seen in countries such as Finland and The Netherlands where people expressed high levels of trust in key players in biobank research (47). Mistrust in the research carried out on the collected samples was also another concern the respondents in this study had received from research participants. Lack of transparency in the research process as well as fears and suspicions of commercialising samples or utilization for non-research purposes have been identified across Africa as hinderances of trust building between biobanks and the communities in which they are located (48).

Wendler et al. (31) reported a 4% respondent concern about the likelihood of selling their samples or using them for non-research purposes including sorcery.

Allocation of biobank staff is still a challenge in low- and middle-income countries due to lack of adequately trained staff to manage health care services. The need for skilled biobank personnel is usually underrated (49). Health professionals with diverse medical backgrounds including pathologists, clinicians, researchers, physicians and nurses are key to the biobanking process, from obtaining donor consent to sample and data collection. Lack of support from health professionals at any stage in the biobank process creates a hurdle in the ability to gather and process high-quality samples (33). One of the respondents in this study, when asked about their feelings towards the collection and storage of samples said,

*‘I think the staff or personnel that are involved in that process for example the biobank staff need to get the proper training and they should be tested and proven to be competent to handle those samples.’. **Male laboratory staff.***

Another respondent was concerned about unqualified sample collectors because he considered sample collection as being paramount and a contributing factor to the research end results.

Several factors including general health and marital status, knowledge of biobanking and past experience with tissue donation significantly influence the willingness to donate biospecimens (35). Similarly, in this study, a person’s current health and marital status seemed to have an influence on the collection, storage and use of samples for research. Significance of a study, religion, culture and beliefs were also found to have the potential to affect collection, storage and use of samples for research. Based on the respondent’s statements, religions like, the Jehovah Witness were found to be hesitant about blood donation because of the belief that they are not supposed to lose blood. The Muslims were thought to be hesitant about studies that would require foreskin because they are believed to only accept circumcision that is carried out from their settings. Also, the Christians were found to be hesitant to receiving medications because of the belief that Jesus can heal them without medication. Cultural beliefs of Africans about the possibility of using samples for sorcery and ritual activities were also found to influence the decisions of some potential participants about sample donation. These statements are not factual and are only perceptions of the respondents that took part in this study.

Generally, the communication of results from researchers to participants was supported in this study. 2 out of 17 of the respondents felt that not all research participants would want to know their research results. Over half of Dutch investigators in a study by Meulenkamp et al. (28) in 2012 concurred with communication of research results to participants with

24% believing that the feedback would help encourage healthy lifestyle. However, more than a third (36%) of the respondents rejected the idea on grounds that personal privacy would be threatened if study participants received individual information. The respondents in this study also supported communication of research outcomes to sample collectors, sample transporters, laboratory and biobank staff as a way to feel involved and improve on their knowledge. 9 respondents supported shipping of samples out of Uganda and only 3 were against it. Understandably, some that supported it preferred if the samples were to be shipped back after testing.

In summary, the study findings illustrate general knowledge about biobanks, and although the respondents were able to describe what biobanks do, there seemed to be a gap in the awareness of all biobanking activities. Additionally, researchers should not only communicate results to participants, but should also inform sample collectors, sample transporters, laboratory and even biobank staff about the different research outcomes through sharing on accessible websites or even through meetings as this can keep the staff rooted in their work and expand their career knowledge.

Limitations

The sample size of this study was relatively small and so the findings of this study do not entirely present the views of all sample collectors, sample transporters, laboratory and biobank staff at MRC and in Uganda.

4.1 Conclusion

Exploring the levels of knowledge of biobanking and the perceptions towards biobanking has helped to identify some of the steps/procedures Uganda and MRC should implement and take on to have better biobanking services. Although many recommendations were suggested, one important aspect to take from all that would be that the biobanks should be transparent about the activities they carry out and what guidelines they follow.

Understanding the concerns raised by the respondents and putting them into consideration can help improve on biobanking in Uganda and at MRC. More biobanks should be established in Uganda as there is growing demand for research and storage of samples.

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Appendix A (Interview guide)

Study title: Perception of Biobanking among sample collectors, sample transporters, laboratory staff and biobank staff at Medical Research Council/Uganda Virus Research Institute and London School of Hygiene & Tropical Medicine Uganda Research Unit

INTERVIEW GUIDE

Demographics:

Profession _____

Qualifications _____

Interview Questions

- 1 Please tell me a little about yourself. (Age, marital status, education, how long you have been working in the field)
- 2 Can you share with me what you know about biobanking?
Probe: (how would you describe a biobank? Are these available in our setting?)
- 3 Can you please describe how you are involved in biobanking of samples/how you are linked to a biobank?
- 4 What is the relevance/importance of biobanking?
(Probe: a) generally b) in our Ugandan setting)
- 5 How do you feel about collection and storage of human samples?
- 6 How do you feel about a biobank sharing samples and sample data with other biobanks or research institutes?
- 7 What is your opinion on the communication of research results from biobanks to participants?
- 8 What concerns do you have towards the collection or storage of human samples?
(Probe: what ethical aspects should be considered during collection or storage of human samples?)
- 9 What concerns have you received from research participants relating to biobanking?
- 10 What can be done to improve on biobanking concept in our setting?
- 11 Do you have any comments or questions?

Appendix B – (Ethical approval)



Uganda National Council for Science and Technology

(Established by Act of Parliament of the Republic of Uganda)

Our Ref: SS469ES

18 August 2020

Phillis Babirye
Medical Research Council/Uganda Virus Research Institute
and London School of Hygiene & Tropical Medicine Uganda
Research Unit
Wakiso

Re: Research Approval: Perception of Biobanking among sample collectors, sample transporters, laboratory staff and biobank staff at Medical Research Council/Uganda Virus Research Institute and London School of Hygiene & Tropical Medicine Uganda Research Unit

I am pleased to inform you that on **18/08/2020**, the Uganda National Council for Science and Technology (UNCST) approved the above referenced research project. The Approval of the research project is for the period of **18/08/2020** to **18/08/2021**.

Your research registration number with the UNCST is **SS469ES**. Please, cite this number in all your future correspondences with UNCST in respect of the above research project. As the Principal Investigator of the research project, you are responsible for fulfilling the following requirements of approval:

1. Keeping all co-investigators informed of the status of the research.
2. Submitting all changes, amendments, and addenda to the research protocol or the consent form (where applicable) to the designated Research Ethics Committee (REC) or Lead Agency for re-review and approval **prior** to the activation of the changes. UNCST must be notified of the approved changes within five working days.
3. For clinical trials, all serious adverse events must be reported promptly to the designated local REC for review with copies to the National Drug Authority and a notification to the UNCST.
4. Unanticipated problems involving risks to research participants or other must be reported promptly to the UNCST. New information that becomes available which could change the risk/benefit ratio must be submitted promptly for UNCST notification after review by the REC.
5. Only approved study procedures are to be implemented. The UNCST may conduct impromptu audits of all study records.
6. An annual progress report and approval letter of continuation from the REC must be submitted electronically to UNCST. Failure to do so may result in termination of the research project.

Please note that this approval includes all study related tools submitted as part of the application as shown below:

No.	Document Title	Language	Version Number	Version Date
1	Consent form	english	2.0	24 April 2020
2	information sheet	english	2.0	24 April 2020
3	interview guide	english	1.0	24 April 2020
4	Project Proposal	English	2.0	

5	Approval Letter	English	2.0	2020-04-24
6	Administrative Clearance	English	2.0	2020-04-24
6	Curriculum Vitae	English	2	22 June 2020

Yours Sincerely



Hellen Opolot

For: Executive Secretary

UGANDA NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY