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Attitudes and practices of researchers on the sharing of genomic data: A qualitative study in Uganda.

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Abstract (350 words)

Background

Global genomic data sharing promotes transparency by enabling wider access to data. However, it raises ethical concerns, particularly in collaborations involving low- and middle-income countries. Despite growing emphasis on data sharing, limited research examines how researchers navigate these ethical complexities. This study explored researchers' attitudes and practices regarding genomic data sharing in collaborative research.

Methods

A qualitative phenomenological design was employed, with key informant interviews (KIIs) conducted between August and December 2023. The study was guided by General Systems Theory (GST) and the Theory of Principlism. GST frames data sharing as part of an interconnected system where multiple components interact within a broader research and governance environment. Principlism offers a lens based on autonomy, beneficence, non-maleficence, and justice. The study was carried out at a university and selected research institutions in Uganda. Institutions and researchers were purposively sampled based on their engagement in genomic research. All interviews were conducted in English, analysed thematically, and managed using NVivo 14. Sixteen KIIs were conducted, with male participants comprising 75% of the sample.

Results

Three themes emerged: First, willingness to share genomic data: most participants (11/16) expressed willingness, commonly motivated by altruism and perceived scientific and societal benefits, aligning with beneficence. A few were hesitant to share data due to fears of data or preferred restricted access owing to concerns about misuse and re-identification risks, reflecting non-maleficence. Second, experiences with data sharing varied: participants described both positive and negative experiences shaped by collaborative arrangements, institutional capacity, and governance structures, consistent with a GST perspective. Third,

attitudes and practices related to selective data sharing emerged, with some researchers emphasizing institutional mechanisms such as policies and data-sharing agreements to regulate access and use and to uphold fairness and justice.

Conclusion

This study underscores the complex nature of genomic data sharing, characterised by both enthusiasm and hesitancy. Enthusiasm was linked to the principle of beneficence and hesitancy reflected the principle of non-maleficence both tied to Principlism. The theory served as a reminder that data sharing should be approached with caution. The GST lens highlights the need to strengthen institutional systems and governance frameworks.

Key words: data sharing, genomic, willingness, hesitancy, ethical, legal, social, Uganda

Introduction

In this research, we define genomics as the study of DNA which are the traits passed on from one generation to another (1). Progress in genomic research has created exciting new opportunities for science including precision medicine (2). Advances in technology have made it possible to generate genomic data faster, more affordably, and in ways that facilitate faster sharing around the globe (3, 4). Data sharing is the practice of making data available to other researchers by adding or combining research participants' data into larger datasets (5). Genomic research requires vast datasets from diverse populations, making collaboration essential. The research is conducted collaboratively because generating and analyzing genomic data requires significant resources, expertise, and technology (6, 7). Within the field of genomics, data sharing encompasses the collection, storage, access and distribution of genomic datasets, frequently facilitated through public or controlled-access repositories (8). Research funders, sponsors and scholarly journals require that genomic sequence data be deposited on public data repositories unless there are justifiable reasons for not sharing like protecting privacy, respect informed consent and prevent misuse (9, 10). While sharing promises to increase research efficiency and maximize the utility of genomic data (4, 11), it raises a host of ethical concerns (12, 13).

Despite global efforts to promote data sharing in genomics, researchers from low- and middle-income countries (LMICs) are often hesitant to share genomic data due to mistrust, historical exploitation, and inequities in collaborative research (8, 14-16).This hesitancy is driven by power differentials, fears of data misuse, protecting privacy, inadequate benefit-sharing mechanisms, and concerns about exploitation (8, 14-16). However, the underlying factors shaping these attitudes and their implications for equitable research remain poorly understood.

Genomic research is relatively new in Uganda but it is making steady progress (17). There are several genomic research capacity-strengthening initiatives in Uganda. For example, the Uganda Medical Informatics Centre (UMIC), one of the largest health research-oriented computational resources in Sub-Saharan Africa that offers state-of-the-art high-performance computing facilities (17). Another example is the African Centre of Excellence (ACE), a secure centralized repository designed for the long-term storage and management of research data https://idi.mak.ac.ug/, (18). These facilities provide robust infrastructure for safeguarding sensitive biomedical and clinical data, including genomic datasets, and are key in the advancement of genomics in Uganda. Despite growing attention to genomic data sharing, there remains limited understanding of empirical research in Uganda exploring researchers' attitudes and practices, as well as the barriers and facilitators shaping these behaviours.

The study aimed to explore the attitudes and practices of researchers in Uganda regarding the sharing of genomic data in collaborative research contexts. Understanding these perspectives is crucial for identifying underlying barriers that may hinder effective data sharing. The study aimed to generate insights that can inform strategies to foster a culture of transparency, trust, and equitable collaboration in genomic research. By critically examining the motivations, concerns, and behaviors of researchers, this work contributes to a deeper understanding of the systemic and individual factors influencing data-sharing practices. These findings, which build on earlier work (6, 19), will help inform the development of guidance document that will support responsible and sustainable genomic data sharing in collaborative research in Uganda and similar low-resource settings.

Theoretical orientation

The study was guided by two theories: the General Systems Theory (GST) that was first proposed by Ludwig von Bertalanffy in 1968 (20) and Principlism (21, 22). According to the GST a system consists of interconnected components (interdependence, feedback, system boundaries, and interactions) that affect one another within a certain boundary and within a larger environment (23). According to Bertalanffy (23), the phenomena is best understood by viewing data sharing as part of a bigger system where different components interact and influence each other, rather than viewing them in isolation. We looked at genomic data sharing as a dynamic system, rather than a series of disconnected actions. Principlism serves as the foundational ethical framework, and is built around four core principles, respect for autonomy, non-maleficence, beneficence, and justice (21, 22). Principlism was used to explain individuals' willingness to share genomic data, addressing ethical dimensions that could not be adequately captured by the GST. This perspective helped us understand how researchers' perceptions (risk, benefits, autonomy and justice) interact with institutional structures (policies, support mechanisms, and broader influences (national and international regulations, commercial interests, and power dynamics) and shape willingness to share genomic data. Both theories guided the development of our research tools, informed our analysis, and structured our discussion of the results.

Methods

Design and reporting.

We used a phenomenological qualitative research design (24) that explored the researchers' lived experiences, attitudes, and practices regarding genomic data sharing in collaborative research in Uganda with genomic research and data sharing. This approach was appropriate because it enabled an in-depth understanding of how researchers perceive and make sense of data sharing within their different research contexts. The research questions and analysis were guided by the Theory of Principlism (22) and the General systems Theory (23). We applied the consolidated criteria for reporting qualitative research

(COREQ) checklist to guide the transparent and comprehensive reporting of our qualitative study (25, 26).

Procedures

Sampling technique

Researchers were identified from a list of 23 genomic specialists obtained from the Uganda National Research Information Management System (NRIMS), a centralized platform maintained by the Uganda National Council for Science and Technology to register all research conducted in the country. Researchers were invited to participate in the study based on their involvement and experience in genomic research. Specifically, we identified those who served as principal investigators or study coordinators on protocols related to host genomics and genetic research. A total of 16 purposively selected genomic researchers who accepted to participate in the key informant interviews.

Tool development

The key informant (KII) guide was developed from the literature on genomics and willingness to share genomic data (5, 13, 27-30). The development of the tool was guided by two theories Principlism (22) and GST (31). Principlism provided an ethical lens emphasizing autonomy, beneficence, non-maleficence, and justice, whereas GST informed understanding of how institutional, collaborative, and individual factors interact to influence data sharing. The KII guide was developed by the lead researcher (DES) and underwent several rounds of review by the co-investigators to ensure relevance and clarity incorporating themes from prior work conducted by the research team (19). The guide was piloted with three individuals, who were excluded from the main data collection, and subsequently revised before commencing the full study. The final guide comprised of both open and closed-ended questions. The section on participant demographics contained closed-ended questions, while the other sections used open-ended questions which were designed to elicit in-depth insights, with additional prompts included to facilitate discussion and probe emerging issues when participants required further guidance in expressing their views. The guide collected information on socio-demographic characteristics, attitudes

toward genomic data sharing, perceptions of data ownership, and factors influencing willingness to share genomic data.

Setting

The study was conducted at a University categorised as an academic institution as well as at research-intensive institutions in Uganda that are actively involved in the conduct of genomic research. These sites were chosen because they host several ongoing and completed genomics studies, have multiple collaborative projects with international partners. Researchers based at these institutions are directly involved in the generation, management, and sharing of genomic data with external partners, making them well positioned to reflect on the practical, ethical, and regulatory dimensions of data sharing. This context made the sites appropriate for examining researchers' attitudes and practices regarding genomic data sharing within collaborative research settings in Uganda. This made the sites suitable for exploring ethical, legal, and social issues surrounding genomic data sharing in the local context.

Data collection, the team and reflexivity

Prospective participants were contacted by phone or email, given a brief description of the study and offered an appointment at their convenience. Written informed consent was obtained before each interview. For virtual interviews, informed consent was obtained before data collection either as a signed electronic consent form sent and returned by email. Data collection was conducted between August 2023 and March 2024. All interviews were carried out in English and lasted approximately 40–45 minutes. Depending on participants' preferences, interviews were conducted either in person or virtually. In-person interviews typically took place in participants' offices or other private but open settings. With participants' consent, all interviews were audio-recorded to ensure accuracy in data capture.

The data collection team comprised of the lead researcher (DES) and two trained research assistants who were not known to the participants to minimize potential bias. The research assistants received training on the study protocol, consenting procedures, and use of the semi-structured interview guide. The study employed research assistants who were not

known to the research participants to avoid bias. The research team held debrief sessions during data collection and analysis to reflect on positionality, including how their professional backgrounds and interactions with participants might shape the study process and findings. The lead researcher was mindful that her role as Principal Investigator interested in genomics and bioethics could influence how interviews were conducted and how the data was interpreted (6). To minimize potential bias, she engaged with peers or advisors to discuss her interpretations of the data. This allowed others to challenge her assumptions and provides an external perspective, ensure the analysis was grounded in the data rather than personal views.

Data Management

The audio recordings were transferred to password-protected computers and deleted from the recorders. All audio recordings were de-identified by removing any personal identifiers such as names, institutions, and specific locations before transcription. The recordings were then transcribed verbatim. The lead researcher was actively involved in the transcription process by verifying each transcript against the original audio recordings to ensure accuracy, completeness, and fidelity to the participants' intended reflections.

Data Analysis

A thematic approach of analysis was conducted through an iterative process which was used in identifying, analyzing and the interpretation of the data because of its ability to help interpret the lived experiences (32). We began by familiarizing ourselves with the interview narratives through repeated reading of the transcripts. Initial codes were generated inductively from the transcripts, based on recurring ideas and concepts in the data. The data was reviewed and grouped into broader themes and sub-themes to capture patterns across participants' experiences. This iterative process allowed continuous comparison between data and emerging themes, ensuring that the final themes accurately reflected participants' lived experiences. A team-based approach was adopted for data analysis, involving the lead researcher DES, ASS and another data analyst, who developed the codebook (28). A preliminary codebook was developed and refined by three experienced researchers leading to the merging and rephrasing of codes and the list of codes was cut

down and merged (33). These codes were then organized into potential themes, which were reviewed, refined, and named based on their relevance to the research objectives. This step-by-step approach allowed for the identification of patterns and deeper meanings within the data. Both inductive and deductive approaches were used in the analysis, guided by the principles of Principlism and GST. Deductive coding was informed by key components of the theories such as beneficence, non-maleficence, and autonomy from Principlism. Inductive codes, on the other hand, emerged directly from the data, with particular attention such as altruism an element of the GST. The data were managed using NVivo software (version 14)(34).

Results

Demographic characteristics of participants

Sixteen respondents participated in the key informant interviews, of which 12/16 were male. Respondents ages ranged between 30- 64 years and were masters and PhD holders as summarized in Table 1. The majority of participants were affiliated with Institution One, identified as the primary site due to its substantial involvement in genomics research. To ensure a broader range of perspectives and experiences, additional participants were purposively selected from other research institutions involved in collaborative genomics work.

Table 1: Summary of researchers' demographics

Characteristic	Category	Frequency (n=16)
Institution Type	Research-intensive	11
	University	4
	Clinical & research-intensive	1
Gender	Male	10
	Female	6
Age Range (years)	30–40	3
	40–50	9
	50–60	1
	60–70	1

Characteristic	Category	Frequency (n=16)
Education Level	Master's degree	6
	PhD	10

Main themes identified

A total of three themes that were identified from the data are summarized in (Table 2). They include: (1) willingness to share genomic data, (2) experiences with genomic data sharing, and (3) attitudes and practices related to genomic data sharing. The first theme, willingness to share genomic data, was categorized into three sub-themes—unconditional willingness, conditional willingness, and hesitancy. These sub-themes were arranged conceptually to illustrate a continuum of participants' views rather than by frequency or numerical representation.

Table 2: Themes on Genomic Data Sharing

Theme	**Sub-Themes**	**codes**	**Theoretical underpinning**
1. Willingness to Share Genomic Data	Unconditional willingness	**Motivational factors:** • Altruism • Perceived benefits of sharing: strong belief in the scientific and societal value of data sharing • Increased publications • Autonomy	**Princplism** Beneficience Autonomy
	Conditional Willingness	Sharing with Conditions: • Willing to share if data is anonymized • Willing to share if there is mutual benefit or reciprocity • Willing to share within trusted collaborations only • Willing to share after embargo periods have expired	**General system theory**

Theme	Sub-Themes	codes	Theoretical underpinning
	Hesitancy	Negative Attitude: Perceived risk Ethical concerns • Fear of data misuse or exploitation • Commercialization	**Principlism** Non-maleficence
2. Experience in Sharing Genomic Data	Positive Experiences	• Beneficial collaborations with respectful data use • Experiences that reinforced trust and a sense of contribution	**General system theory** Feedback with Previous experiences
	Negative Experiences	• Fear of data misuse or exploitation • Data misuse or breaches of agreement • Feelings of exploitation, regret, or being excluded from follow-up work	Principlism Non-maleficence
3. Attitude and practices in the Sharing of Genomic Data	Platforms and Mechanisms	• Data shared via institutional platforms or consortium networks • Use of formal agreements and secure systems for data exchange	**General system theory** Feedback on practice
	Positive attitude	• Data sovereignty is a good thing. My institutional polices are adequate •	**General system theory** Feedback on positive attitude
	Resources and Capacity	• Availability or absence of infrastructure, skilled personnel, and funding • Gaps in technical and regulatory capacity hindering effective sharing • Legal support	**General system theory** System boundaries Interdependence

1. **Willingness to share genomic data**

Willingness to share data was categorized as unconditional willingness, conditional willingness, and hesitancy.

Unconditional willingness to share genomic data

The key informant interview findings showed that most of the participants (11/16) expressed unconditional willingness to share genomic data. A deeper analysis of their reflections suggests that this willingness was actively shaped by a combination of motivational drivers. These included a low perception of risk, a strong sense of altruism, perceived benefits such as scientific advancement perceived efficiency of data reuse.

Researchers who expressed unconditional willingness to share genomic data often viewed the risks of re-identification as minimal, largely because they believed the data had been sufficiently de-identified and that large-scale genomic sequencing in the country was still limited. This sense of safety aligned with the principle of non-maleficence, reinforcing their confidence that sharing data would not cause harm. Their willingness was also driven by altruism and a desire to advance scientific progress, particularly by empowering early-career scientists in LMICs. Many saw data sharing as a way of giving back to the community and reciprocating the support received from donors and collaborators. The perceived benefits of sharing data were described at individual, material, and financial levels. Individual benefits included professional visibility, expanded collaborations, and opportunities for publication; material benefits encompassed scientific advancements such as improved medical interventions and drug development; and financial benefits were linked to potential gains from the commercialization of data. Several participants emphasized that data sharing enhances research efficiency, minimizes duplication, and accelerates innovation by allowing others to build on existing knowledge. A sense of autonomy and agency in deciding how data are accessed, reused, or credited further strengthened their trust and willingness to participate in data sharing. Data sharing was viewed as a way of giving back to the community and this sense of reciprocity aligns with the idea of promoting the common good.

One participant highlighted how a non-financial benefit such as being part of a team that contributed to scientific discovery could sooth the soul of the researcher and encourage more data sharing

> *From a scientific perspective, the benefit you can get is that you can be part of a team that has made a discovery. Unfortunately, some of those things don't have any monetary reward but they can soothe your soul. Maybe one day you will win a Nobel*

prize who knows. Unfortunately, even the Nobel prize money is usually given back to research or something like that (KII 02).

Conditional willingness

While some participants were open to sharing genomic data, their willingness was moderate. This conditional willingness stemmed from the sensitive nature of genomic data, and many felt that sharing should only happen with appropriate safeguards in place or restrictions such as controlled access. Additionally, they indicated that data should not just be shared with random people because you lose the control. They cautioned about the need to nurture a relationship with people or collaborators before sharing the data. Several researchers raised concerns about misusing data and mentioned imposing an embargo period, during which data was only accessible to consortium members. The suggested embargo period was approximately three to four years, which would enable them to engage in their analysis and publish their findings before making the data publicly available. Furthermore, some researchers had no choice but to share their genomic data because they didn't have the expertise and capacity to analyze and interpret their data independently.

The key informants noted that they would only share data after filing patents. Others indicated that they would only share data upon reasonable request, emphasizing that sharing should serve a legitimate purpose.

Only when we publish or get the patent out, is when we can share the data. But if we haven't yet reached that scenario and should we sense that if we share this data we can lose IP (Intellectual Property) or if there are parties or some of our co-investigators are not open to sharing, we will put an embargo. But that embargo must have a defined period (KII 07).

Hesitancy to share genomic data

Observations from the data revealed that participants identified several ethical concerns related to genomic data sharing, largely due to the sensitive nature of the data. Researchers

emphasized key issues such as the risk of misuse, re-identifiability, and potential loss of privacy not just for individual participants, but also for their families and communities. They stressed the importance of ongoing, transparent, and culturally appropriate informed consent processes to ensure participants clearly understand what they are agreeing to. Concerns about deceit, plagiarism, and lack of recognition reflected a broader mistrust in how the data might be used or credited. In some cases, participants' unwillingness to share genomic data stemmed from fears that the data could be sold, shared with commercial companies, or used in ways that perpetuate inequities in benefit sharing.

One researcher attributed hesitancy to share genomic data to the craftiness of some people who may misuse the data by selling it with commercial companies as well as inequity in terms of benefits and access of products.

> *I worry because there are people who are unscrupulous and can commercialize what was a free service. The argument against, mostly rotates around things to do with commercialization and equity of access after products are made out of this information which is also understandable. But in terms of benefit from the commercialization process, I think that concept is one that I feel is new and not really well understood, at least in our context here (KII 15).*

2. Experience in the sharing of human genomic data

In line with the phenomenological approach, participants were selected based on their lived experience with genomic research and data sharing. All 16 participants had been involved in genomic research and had either directly shared data or participated in projects where genomic data sharing occurred. While the majority of the participants (11 out of 16) had shared genomic data, all participants were able to reflect on and describe their experiences, observations, and perceptions of data sharing practices within genomic contexts. Some indicated that they shared the data on individual basis while others shared it as a part of collaborative research. Several participants noted that formal data sharing agreements were drafted, signed, and subsequently reviewed by the institutional review board (IRB) to ensure

compliance with ethical standards. They emphasized that shared data is usually in an intermediary form or analyzed, but rarely in the raw form. They indicated that they primarily shared the genomic data through cloud platforms, emails, repositories, and institutional servers.

One participant shared that they had a positive experience in the sharing of genomic data.

> *We haven't had any issues as far as either breach of confidentiality, data being published without our knowledge, samples being analysed without consent, from all the parties involved* (KII 01).

Another participant shared an experience where through working with a collaborator from a high-income country, he helped him realize that his work presented something novel

> *We shared the data with someone, and then he said, did you realize you have this novel kind of finding? We said no, and he said, try to analyze it again, I did ABCD and this is what I found. So, it came back and then we run the analysis again and see we managed to find something that was even more impactful than what we thought (KII 13)*

While acknowledging a previous positive experience with genomic data sharing, some participants expressed concern about potential of infringement of intellectual property rights and emphasized the need to publish findings before depositing data on genomic platforms.

> *I have experience in sharing data. We have shared data before on several platforms because there are many on which we post our data. Now once a study is published, we rush to disseminate or share it on platforms or in conferences. We first publish the protocols online or on platforms, because it is very easy for people to violate the intellectual property rights and quickly do that research and publish it before you do anything (KII 06).*

3. Practice in the sharing of genomic data

Insights from the data showed that participants shared mixed feelings about data sovereignty. Whereas some perceived data sovereignty as a means of keeping control of data within the country of origin, to protect national interests and maintain power, other participants, felt that it could limit research and make collaboration more difficult. Many pointed out that true data sovereignty would be hard to achieve as long as the country continues to rely heavily on donor funding given to them. Sovereignty comes with vulnerability, power, money, and resources. On the other hand, there was a sense of optimism, with some participants noting that the Ugandan government has started allocating resources to support local researchers which they thought was critical in attaining sovereignty.

In addition, the findings revealed that institutional structures and systems strongly influence how genomic data are shared. They noted that some institutions can determine who has access to data, how it is managed, and under what conditions it can be shared, shaping both opportunities and constraints in collaborative research. They noted that most institutions adopt a decentralized approach to governance, developing internal guidelines aligned with their specific mandates and capacities. This autonomy promotes accountability and data stewardship, supported by investments in building internal capacity to analyze and monitor data use. They also highlighted that data sharing agreements (DSAs) emerged as a key control mechanism. While some institutions have well-established templates and review procedures, others lack formalized processes. Funders and RECs were reported to play a vital role by requiring and reviewing DSAs and data management plans to ensure fairness, protect participant rights, and balance institutional interests.

Also, variations were noted in data storage infrastructure. Some institutions had advanced systems for data management and secure storage, while others relied on external repositories such as PubMed or NCBI. This concentration of capacity highlights the need for broader national investment in genomic data infrastructure.

Finally, some researchers described practicing selective data sharing—disclosing only specific components of datasets while withholding sensitive contextual information. Viewed through the GST lens, this reflects institutional adaptation to maintain balance between

openness and ethical responsibility within a complex system of collaborators, funders, and oversight bodies.

Participants emphasized the importance of sharing genomic data responsibly, noting that not all associated information needs to be disclosed. In particular, they advocated for retaining control over metadata such as sample origin, contextual details, and participant identifiers which can carry sensitive implications.

> *I retain the metadata which can be very informative. When you are accessing genomic data without the metadata; it may not be of much use to you. So, it is the metadata combined with the genomic data that has a lot of power. If I just give you sequence data without the metadata, how much can you do? But if I give you everything, then I mean, I am at your mercy especially if I am vulnerable (KII 10).*

Discussion

This study explored the attitudes and practices of researchers in Uganda regarding the sharing of genomic data in collaborative research contexts. Overall, willingness to share data was predominantly high, there were instances of low and conditional willingness. Using General Systems Theory (GST) and Principlism as guiding frameworks, the study examined how institutional, social, and ethical dynamics interact to shape researchers' attitudes and practices (35). Genomic data sharing emerged not as an isolated act but as part of an interconnected system involving researchers, institutions, and regulatory bodies, each influencing the others through feedback mechanisms of trust, capacity, and governance.

Our findings underscore the importance of understanding genomic data sharing not as an isolated activity, but as part of a broader interconnected system involving researchers' institutions, and regulators within a wider research environment central in influencing how genomic data is shared. This perspective aligns with GST developed by Von Bertalanffy (20), which emphasizes the interdependence of components within a system and how institutional structures influence individual and collective behaviors. In the context of genomics research, effective data sharing depends on dynamic interactions among actors,

shaped by policies, ethics oversight, legal frameworks, and institutional norms. These feedback mechanisms ensure the system remains adaptive, responsive, and trustworthy. Additionally, applying the ethical framework of Principlism provided further depth to our analysis by highlighting how perceptions of autonomy, justice, and potential risks or benefits influence researchers' willingness to share data. Together, these frameworks guided by GST emphasize that fostering a culture of responsible data sharing requires not only technical and regulatory mechanisms, but also attention to the ethical values and systemic conditions that shape practice.

Willingness to share genomic data was largely motivated by perceived benefits such as accelerated scientific discovery, avoidance of redundant research efforts, and enhanced collaboration. These motivations align with the ethical principle of beneficence (22), which emphasizes the obligation to promote societal good and maximize potential benefits. Participants' emphasis on data sharing as a way to advance science and improve health outcomes reflects a commitment to contributing to societal and scientific good key aspects of beneficence. The literature shows that researchers are willing to share genomic data because it increases their visibility, enhances collaboration and optimizes utilization which aligns with our findings (36, 37) . In contrast to our findings, (38) in a large survey from 22 countries reported low willingness to share data across populations worldwide. This difference could be attributed to the methodology as well as distinct contextual factors in our study setting. Other possible reasons for the differing findings include variations in participants' familiarity with genomics and cultural or societal perceptions of data sharing, which are likely to differ between global online participants and those engaged more deeply in local research settings like ours.

As reported in the literature, our findings suggest that several researchers are willing to share data for altruistic reasons and the perceived benefits that can be derived (14, 39, 40),. This willingness reflects the ethical principle of beneficence as researchers hope their contributions will advance scientific knowledge and support the development of new drugs and vaccines ultimately aiming to improve public health outcomes (21, 22).

The findings underscore the importance of individual autonomy in genomic data sharing. Researchers who believed they would be involved in decisions regarding the future use of

shared genomic data expressed a greater willingness to support data sharing. This finding aligns with the ethical principle of autonomy (21), extending beyond research participants to include researchers themselves as key decision makers in the data-sharing process. Researchers who felt they had a voice in how data was shared particularly in collaborative settings expressed a higher willingness to engage in genomic data sharing. Researchers who believed they bore responsibility for protecting participants' data demonstrated a stronger commitment to ensuring data sharing was conducted ethically and transparently.

Institutional differences significantly shaped data sharing practices. For instance, some institutions encouraged openness and collaboration through flexible policies, while others especially the larger, research-intensive institutions, enforced strict governance mechanisms due to concerns over intellectual property, data misuse, or past negative experiences. Within the GST, such institutional controls represent system boundaries that regulate interactions and preserve system integrity. These institutional differences may stem from concerns about intellectual property, prior experiences with data misuse, or institutional cultures that encourage caution. These findings are consistent with previous research by Graham (2022), which demonstrated that an institution's character including its aims, values, culture, and governance structures strongly influences its approach to data sharing. Together, these insights emphasize the critical role of institutional and governance frameworks in promoting or constraining the sharing of genomic data. Institutional control mechanisms such as policy development and data sharing agreements serve as key mechanisms through which organizations shape researcher behavior and foster a sustainable culture of responsible data sharing.

Researchers expressed conditional willingness to share genomic data, largely contingent upon assurances of de-identification, secure storage, and restricted access. This cautious approach reflects adherence to the principle of non-maleficence, as researchers sought to minimize potential harm and protection of participants' confidentiality through preventing misuse, re-identification, or unauthorized access to sensitive data. These findings are consistent with studies conducted in South Africa, which highlighted the importance of robust governance systems, including the presence of data sharing agreements and restricted or regulated scientific databases with controlled access (41-43). These systems are essential for protecting both research participants and LMIC-based researchers,

ensuring that collaboration is built on trust, fairness, and mutual benefit. Our findings also align with literature calling for equity in data-sharing partnerships between researchers from LMICs and high-income countries particularly in contexts where disparities in infrastructure and analytical capacity limit local autonomy (44, 45).

Limited infrastructure, inadequate funding, and a shortage of skilled personnel were cited as major barriers to effective genomic data sharing. These challenges highlight the interdependence of system components within GST, where one element's weakness such as lack of technical capacity affects the overall system's efficiency. This imbalance in skills and resources not only limits their autonomy in collaborative relationships (21). These findings agree with research on the challenges faced by researchers in Africa, including the inability to process and analyze large-scale genomics data on the continent, because this requires highly specialized skills and expensive computing infrastructure (4). Some researchers reported feeling compelled to share data with external collaborators due to insufficient local capacity for data analysis. This finding underscores the importance of investing in local infrastructure, fairer data sharing systems developed collaboratively by researchers, institutions, and policymakers and human resource development to ensure meaningful participation in global genomics research. This will ensure ethical protection and meaningful participation for LMIC researchers. These findings contrast with Mboowa, Sserwadda (46) who reported significant progress across the African continent including large-scale sequencing efforts led by African scientists, the establishment of infrastructure like biobanks and biorepositories, and substantial investment in training early-career researchers in analytical skills through initiatives such as H3Africa (46). Nonetheless, more equitable distribution of resources for researchers from LMICs remains necessary to reduce dependency and strengthen local autonomy to avoid situations where they feel pressured to share the data.

Despite overall willingness, some researchers expressed hesitancy or refusal to share genomic data consistent with the observations made by Middleton et al. in in a global survey (38). This reluctance stemmed from concerns about data misuse, re-identification, inequitable benefit sharing, and profit-driven exploitation concerns surrounding data sharing that are prevalent (38) . This is particularly evident in relation to issues of trust, negative attitudes, and perceived risks associated with such practices (38). These concerns reflect

fear of unethical practices, which may negatively affect willingness to share genomic data. The findings indicate that the reluctance to share genomic data were attributed to the sensitive nature of genomic information presenting potential risks related to re-identification, data misuse and the erosion of privacy. The lack of trust could stem from fears that genomic data could be sold for profit, with little regard for how the proceeds or benefits are shared. The findings concur with a study(47), which showed that such commercialization raises concerns about data misuse. Moreover, when research participants and researchers from LMICs are excluded, it often results in unequal access to the benefits derived from the data. . In line with the GST, this study argues that genomic data should be shared, provided there are well-coordinated institutional systems including clear policies, ethical oversight, and collaborative structures that ensure responsible and equitable use. In line with the principle of non-maleficence, shared participant data should be safeguarded to prevent breaches of confidentiality and protect individual privacy.

Taken together, these findings reveal that genomic data sharing in Uganda operates within a complex and interdependent system of ethical principles, institutional frameworks, and individual experiences. The integration of GST and Principlism highlights that fostering a culture of responsible and equitable genomic data sharing requires strengthening institutional feedback mechanisms such as trust, governance, and capacity; while upholding the ethical principles of beneficence, autonomy, and non-maleficence. Building such a system will demand coordinated efforts among researchers, institutions, and policymakers to promote both scientific advancement and ethical integrity in the evolving field of genomic research.

Strengths and limitations of the study

The main strength is the inclusion of participants with direct, lived experience in the conduct of genomic research, which enriched the findings with contextually grounded and practice-informed perspectives. Furthermore, the use of Theoretical grounding which was used in the development of tools, data collection, analysis and report writing.

The limitation of the study is that participants may have responded in ways they perceived as socially desirable, especially on sensitive issues like ethics and data sharing. To mitigate this, interviews were conducted in a private setting by experienced social science researchers who emphasized confidentiality, anonymity, and the absence of right or wrong answers, thereby fostering trust and openness. Also, the paper reports only views of researchers yet the views of other stakeholders like research participants and regulators could have ensured representativeness which may limit the comprehensiveness of stakeholders' views. However, triangulation with ongoing related work involving a broader range of stakeholders is being undertaken, and some findings have already been published (6, 19). These complementary efforts will contribute to the development of a more holistic, evidence-informed guidance paper on genomic data sharing in Uganda.

This process allowed for refinement of the questions, ensured contextual relevance, and enhanced respondent understanding contributing to the overall credibility of the study findings.

Conclusion

This study highlights the complex dynamics of genomic data sharing, characterized by both willingness and hesitancy among researchers. While many participants viewed data sharing as a means to advance science and improve health reflecting beneficence they also expressed concerns about ethical, legal, and social risks tied to non-maleficence. Addressing these concerns requires robust data governance structures, clear ethical frameworks, and equitable access mechanisms. Guided by General Systems Theory, institutions should strengthen policies, standardize data-sharing procedures, and invest in capacity building to create an environment that supports responsible and fair data sharing. Ultimately, effective genomic data sharing depends on a coordinated and responsive system that balances openness with protection for all stakeholders.

Statements and Declarations

Conflict of interest Disclosure

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Data availability statement

Data is provided within the manuscript and the data collection tool was uploaded as a supplementary item.

Compliance with Ethics Guidelines

The study was approved by the Makerere University Higher degrees committee School of Biomedical Sciences Research ethics committee (SBSHD-REC 2022-273) and the Uganda National Council for Science and Technology (SS1730ES). All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (48). Informed consent was obtained from all patients for being included in the study. For interviews conducted virtually, before the start of each call, we confirmed that the participant was in a safe and private space where they could not be overheard before we proceed with the interview (6).

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Authors' contributions

DES: Led the writing, contributed to conceptualization, participated in data collection, took part in analysis, critically reviewed and provided feedback on drafts and provided final approval

IM: Provided guidance regarding direction, critically reviewed drafts, gave feedback, and granted final approval.

DK: Critically reviewed, and provided feedback on drafts and provided final approval

MN: Critically reviewed, and provided feedback on drafts and provided final approval.

ASS: Participated in data analysis, critically reviewed, and provided feedback on drafts and provided final approval.

DKM: Critically reviewed and provided feedback on drafts and final approval.

SS: Contributed to conceptualization, contributed to the writing, critically reviewed, and provided feedback on drafts and final approval.

EM: Oversaw the writing, contributed to conceptualization, contributed to analysis, contributed to the writing, critically reviewed, and provided feedback on drafts and final approval.

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