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Bioethics training needs assessment for HIV research in vulnerable populations: a survey of trainees at college of health sciences, Makerere university

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Abstract

Background Research involving vulnerable populations of people living with HIV (PLWH), such as children, adolescents, older adults, pregnant and lactating women, hospitalized patients, and key populations, presents complex bioethical challenges. We assessed bioethics training needs for trainees engaged in HIV research from the School of Medicine (SoM) of Makerere University and the Infectious Disease Institute (IDI) to inform the development of a comprehensive bioethics training program for trainees.

Methods A cross-sectional quantitative study was conducted from March to May 2024 using an online structured questionnaire distributed via Google Forms. Participants included former and current trainees who have conducted research with PLWH within the past five years. Data collected included self-rated bioethics knowledge, frequency of encountering bioethical challenges, confidence in addressing challenges across vulnerable populations, and preferred training topics and delivery formats. Descriptive data analysis was performed using STATA Version 17.

Results We attained a response rate of 67.5% (108/160). While 75.9% reported formal bioethics training, 58.3% rated their knowledge moderate. Frequently encountered challenges included maintaining confidentiality and privacy (61.1%), conducting informed consent processes (56.1%), applying bioethical principles, engaging with communities (54.6%), and selecting appropriate research participants (51.4%). Confidence in addressing bioethical challenges was notably lower for vulnerable populations than for general HIV research. Confidence of the trainees was higher in research involving older PLWH and pregnant/lactating women, moderate with children/adolescents and hospitalized individuals, and very low with key populations. Trainees expressed limited confidence in addressing cultural sensitivity, stigma, coercion, community engagement, harm monitoring, and compensation for research-related harm across all the populations. Top training priorities included ethical issues with research involving vulnerable populations (97.2%), reporting ethical concerns (94.4%), community engagement (93.6%), research on stored samples/data (94.5%), and stigma/discrimination (92.6%). Preferred formats were in-person workshops, interactive case-based scenarios, and online courses.

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Conclusion Trainees faced diverse bioethical challenges and exhibited varying confidence levels in addressing these issues across different vulnerable populations. These findings underscore the need for targeted, context-specific bioethics training tailored to conducting research with vulnerable PLWH. This study has informed the development of a comprehensive training program to improve the ethical conduct of HIV research in Uganda.

Clinical trial number Not applicable.

Keywords Vulnerable populations, Bioethical challenges, HIV research, Bioethics training, Uganda

Introduction

Research involving vulnerable populations of people living with HIV (PLWH) in resource-limited settings (RLS) poses unique and complex bioethical challenges [1, 2]. Vulnerable populations include children, adolescents, pregnant and lactating women, older adults, hospitalized patients, and key populations, usually identified as sex workers, gay, bisexuals, and other men who have sex with men (GBMSM), transgender individuals, and people who inject drugs (PWID) [3, 4]. These groups often face compounded vulnerabilities due to stigma, discrimination, and legal and social marginalization, necessitating tailored ethical considerations to safeguard their rights and well-being [2, 5–7]. In developing countries, vulnerabilities are further exacerbated by factors such as low literacy, limited access to healthcare, and socioeconomic disparities, where individuals may agree to participate in research without fully understanding its implications or in hopes of accessing otherwise unavailable resources [4]. The stigmatization and criminalization faced by some of these vulnerable populations, in many SSA settings, poses bioethical challenges during the design and implementation of studies intended to expand coverage of prevention strategies, increase treatment uptake, and improve retention in care [6, 8–11].

Research involving human participants is often required for graduate students in academic Sub-Saharan institutions. At Makerere University, College of Health Sciences, trainees frequently conduct research involving PLWH. However, the current curriculum lacks structured bioethics training tailored to the unique challenges of research with vulnerable populations of PLWH. Although foundational frameworks like Good Clinical Practice (GCP) and Human Subjects Protection (HSP) offer basic ethical guidance, they fail to address the complex, nuanced issues trainees face during research implementation. This gap leaves trainees underprepared, potentially leading to inconsistent ethical practices and challenges in safeguarding participants' rights during research [12–16]. Many faculty members also lack formal training in research ethics, compromising their ability to supervise student research effectively [17]. These deficiencies underscore the urgent need for targeted training to navigate the ethical complexities of research involving vulnerable populations.

We assessed the bioethics training needs of master and PhD trainees engaged in HIV research at Makerere University, College of Health Sciences- School of Medicine and the Infectious Diseases Institute (IDI). The purpose was to inform the development of a robust, context-specific bioethics training program to better prepare trainees for ethical research practices among vulnerable populations of PLWH in Uganda.

Methods

Study design and setting

We conducted a descriptive cross-sectional quantitative survey between March and May 2024 to assess bioethics training needs among trainees at the School of Medicine (SoM) and the Infectious Diseases Institute (IDI), both under the College of Health Sciences at Makerere University. SoM trains a large cohort of graduate students across various clinical and public health disciplines, many of whom engage in research involving people living with HIV (PLWH) as part of their academic programs. In contrast, IDI is a specialized research institute affiliated with Makerere University, recognized as a center of excellence in HIV care, treatment, and research. All IDI trainees are directly involved in HIV-related research projects. Including trainees from both institutions enabled a comprehensive assessment of bioethics training needs among a diverse group of individuals actively engaged in clinical HIV research across academic and clinical environments.

We employed two main strategies to identify eligible participants from the School of Medicine (SoM) and the Infectious Diseases Institute (IDI). First, we obtained lists of current and former trainees from both institutions, which included names, contact information, and dissertation titles. We reviewed departmental graduation lists since 2019. This process yielded a total of 630 trainee contacts—546 from SoM and 84 from IDI. We then screened dissertation titles to identify those related to HIV research, resulting in 160 eligible participants. To supplement and verify HIV research involvement, we conducted an independent search of the Makerere University Institutional Repository, where all students are required to upload their dissertations.

To confirm eligibility, we conducted an independent search of the Makerere University Institutional Repository (Mak-IR), where all student dissertations are

archived. At IDI, all trainees were automatically eligible since their training is exclusively HIV-focused. Inclusion criteria were: [1] current or former postgraduate trainees at SoM or IDI between 2019 and 2024, and [2] documented involvement in HIV-related research, demonstrated by defended proposals, archived dissertations in Mak-IR, or departmental confirmation of ongoing HIV research. Exclusion criteria included trainees who had been formally terminated by either institution for academic or disciplinary reasons.

Only eligible trainees ($N = 160$) were contacted via email and followed up with telephone contact to inform and request their participation in the study. The survey was administered online using Google Forms. A survey link was sent to each participants' email integrated with an electronic informed consent form that provided comprehensive information about the study.

Data collection

We developed a new structured, questionnaire informed by review of literature on ethical issues HIV research incorporating key themes relevant to working with vulnerable populations. For each population, we used a 16-item checklist of key bioethical issues that were identified through literature review [1, 9, 18–21]. The tool was piloted with 20 participants with similar characteristics to the target study population who provided feedback on item clarity, relevance, and comprehensiveness. Minor revisions were made based on pilot feedback, including rewording of ambiguous items and refining response scales to enhance usability and comprehension. Reliability testing of the pilot responses showed strong internal consistency of the survey tool, with a Cronbach's alpha of 0.98. We collected data on demographic characteristics (age, education background, sex, affiliated institution, HIV research experience, and primary vulnerable population focus), self-rated knowledge of bioethics in HIV research, frequency and confidence in addressing bioethical challenge in addressing bioethical challenges across five vulnerable populations (children & adolescents, older adults, pregnant and lactating women, hospitalized patients, and key/sensitive populations). Responses were recorded on a 5-point Likert scale. We also assessed training needs and preferences through preselected topics and participant-suggested recommendations.

To minimize missing data, we configured the survey tool to require responses to all questions before submission. To enhance the response rate, weekly email and telephone reminders were sent throughout the study.

Data analysis

Survey data were exported to STATA Version 17 for analysis. Descriptive statistics were used to summarize participants' demographic characteristics, self-rated knowledge of bioethics, frequency of encountering bioethical challenges, and confidence in addressing these challenges. Categorical variables were summarized using frequencies and percentages. To explore subgroup differences, we conducted chi-square (χ^2) tests of independence to examine variations in participants' confidence in addressing selected bioethical challenges across five vulnerable populations.

For analytical clarity and to simplify reporting, the original 5-point Likert scale was collapsed into a 3-point scale. "Very confident" and "Confident" responses were combined into a single "confident" category, while "not confident" and "not confident at all" were grouped under "not confident." The "neutral" category was retained. This approach was deemed appropriate given the exploratory nature of the study and the need to identify broad training needs rather than capture fine-grained distinctions. This decision is consistent with recommended survey practices, particularly in contexts where response distributions are skewed or where collapsing improves cell size and interpretability [22]. We acknowledge that this transformation may have reduced the granularity of the data, potentially limiting the ability to detect subtle variations in confidence levels. This has been noted as a study limitation.

To assess differences in participants' confidence in addressing bioethical challenges across the vulnerable populations, we conducted subgroup comparisons using Chi-square tests of independence. For each of the 16 bioethical challenge items, confidence levels were compared across the population groups. A p-value of < 0.05 was considered statistically significant.

Results

Of 160 participants contacted, 108 (67.5%) responded to the survey. The majority (61%) were former trainees, 57% were men, and most (96.2%) were aged 25–45 years and held a master's degree (86.1%) (Table 1).

Frequently encountered bioethical challenges

The most frequently encountered bioethical challenges reported by participants were maintaining confidentiality and privacy (61.1%), conducting the process of informed consent/assent (56.1%), applying bioethical principles such as autonomy, beneficence, and justice (54.6%), community engagement (54.6%), determining the relevance of research to local health needs (53.7%) and appropriate selection of research participants (51.4%). The less frequently encountered challenges included issues related to stigma and discrimination (45.8%), reporting ethical concerns (33.4%), incentives, undue inducement, coercion (32.7%), and harm monitoring and compensation for damages (22.5%). (Table 2)

Table 1 Demographic characteristics and previous HIV research experience of the trainees ($n = 108$)

Characteristics	Frequency/ Percent
Sex	
Women	46 (42.6%)
Men	62 (57.4%)
Age	
25–35	52 (48.1%)
≥35–45	52 (48.1%)
≥45–55	4 (3.7%)
Highest education level	
Master	93 (86.1%)
PhD	13 (12.0%)
Post Doc	2 (1.9%)
Trainee status at IDI or School of Medicine	
Current trainee	42 (38.9%)
Former trainee	66 (61.1%)
Duration in HIV research (Years)	
1–5	61 (56.5%)
≥ 5–10	31 (28.7%)
≥ 10–15	16 (14.8%)
Type of HIV research conducted*	
Basic Science Research (Virology, Immunology, Genetics)	31 (28.7%)
Clinical trials	33 (30.6%)
Observational/Epidemiological Studies	103 (95.3%)
Implementation Science Research	20 (18.5%)
Social and Behavioral Science Research	17 (15.7%)
Others	1 (0.9%)
Participants involved in HIV research among vulnerable populations*	
Children and Adolescents	31 (28.7%)
Key Populations (GBMSM, CSW, transgender individuals, PWID)	11 (10.2%)
Older adults	36 (33.3%)
People living with co-infections (e.g. TB, hepatitis)	39 (36.1%)
Pregnant/lactating women living with HIV	25 (23.1%)
Sick and hospitalized patients	11 (10.2%)
Others	15(13.8%)
Prior Formal Bioethics Training	
Yes	82 (75.9%)
Self-rating of current knowledge of Bioethics in HIV Research	
Low	13 (12%)
Moderate	63 (58.3%)
High	32 (29.6%)

CSW-Commercial Sex Workers, **PWID**-People who inject drugs; **GBMSM**-Gay bisexual and other men who have sex with men; *Participants could select multiple categories

Confidence in addressing bioethical challenges

In conducting general HIV research, participants reported high confidence in conducting the informed consent process (91.7%), maintaining confidentiality and privacy (93.5%), applying bioethical principles (82.4%), and fulfilling the role and responsibility of researchers in protecting participants (82.4%). However, confidence was notably lower in addressing challenges related to stigma and discrimination (58.3%), reporting ethical concerns (58.3%), community engagement (58.3%), understanding the role of regulatory frameworks (53.7%), assessing risk and benefits (46.3%), harm monitoring and compensation for damages (46.3%), and cultural sensitivity (46.3%). (Table 2)

Despite the high confidence levels observed for general HIV research, there was a significant drop and variation in confidence levels across all bioethical challenges among vulnerable populations. Higher confidence was observed in contexts involving older PLWH, pregnant/lactating women, moderate confidence for children/adolescents and hospitalized individuals, and very low confidence for key populations (< 55%). Challenges such as maintaining confidentiality and privacy and applying principles of autonomy, beneficence, and justice) were areas of higher confidence (73-85%) for older PLWH and pregnant/lactating women. Lower confidence (29–44%) was reported for addressing cultural sensitivity, stigma and discrimination, and harm monitoring and compensation for damages for key populations. Confidence was moderate (60-70%) for issues such as reporting ethical concerns, assessing risk and benefits, and ensuring appropriate participant selection across all populations, highlighting specific areas requiring targeted training and capacity building, particularly when engaging with key populations and hospitalized patients (Table 3). Statistically significant differences ($p < 0.05$) were observed in most areas, except for research on stored samples/data ($p = 0.150$), where confidence levels were similar across groups (Table 3).

Recommendations for bioethics training in HIV research

In-person workshops were the preferred (60.1%) modality of training, followed by online courses (53.7%) and interactive case-based discussions (46.3%). Participants showed strong interest in a wide range of bioethics topics for inclusion in the curriculum, with the highest levels of interest reported for ethical issues in research involving vulnerable populations (97.2%), reporting ethical concerns (94.4%), community engagement in research (93.6%), and stigma and discrimination (92.6%). Topics such as research on stored samples/data (94.5%), harm monitoring and compensation for damages (90.7%), and assessing risk and benefits (89.8%) also garnered significant interest. While other areas had lower preferences, they still reflected a substantial interest (75% and above). (Fig. 1).

Participants suggested several additional topics for inclusion in the bioethics curriculum, including ethical considerations in clinical trials for HIV care, the role of research ethics committees, community engagement in sensitive populations, multi-sectoral collaboration, and

Table 2 Frequency of encountering the following bioethical challenges in HIV research and confidence in addressing the selected challenges ($n = 108$)

Bioethical Issue/ Challenge	Frequency of encountering bioethical challenges (frequency/Percentage)				Confidence in addressing the challenges (frequency/percentage)		
	Never	Rarely	Occasionally	Frequently	Not Confident	Neutral	Confident
Conducting the process of informed consent	11 (10.3%)	30 (28.0%)	6 (5.6%)	60 (56.1%)	3 (2.8%)	6 (5.6%)	99 (91.7%)
Applying bioethical principles*	15 (13.9%)	23 (21.3%)	11 (10.2%)	59 (54.6%)	6 (5.6%)	13 (12.0%)	89 (82.4%)
Maintaining Confidentiality and privacy	12 (11.1%)	22 (20.4%)	8 (7.4%)	66 (61.1%)	1 (0.9%)	6 (5.6%)	101 (93.5%)
Stigma and discrimination	13 (12.1%)	30 (28.0%)	15 (14.0%)	49 (45.8%)	15 (13.9%)	23 (21.3%)	70 (64.8%)
Incentives, undue inducement and coercion	22 (20.6%)	27 (25.2%)	23 (21.5%)	35 (32.7%)	17 (15.7%)	28 (25.9%)	63 (58.3%)
Role and responsibility of researchers	13 (12.0%)	23 (21.3%)	17 (15.7%)	55 (50.9%)	6 (5.6%)	13 (12.0%)	89 (82.4%)
Reporting ethical concerns	17 (15.7%)	33 (30.6%)	22 (20.4%)	36 (33.4%)	15 (13.9%)	17 (15.7%)	76 (70.4%)
Conducting research on stored samples/data	28 (25.9%)	12 (11.1%)	16 (14.8%)	52 (48.1%)	23 (21.3%)	22 (20.4%)	63 (58.3%)
Assessing risk and benefits	15 (14.0%)	22 (20.6%)	22 (20.6%)	48 (44.9%)	10 (9.3%)	20 (18.5%)	78 (72.2%)
Harm monitoring and compensation for damages	36 (33.6%)	23 (21.5%)	24 (22.4%)	24 (22.5%)	27 (25.0%)	31 (28.7%)	50 (46.3%)
Relevance of research to local health needs	14 (13.2%)	13 (12.3%)	22 (20.8%)	57 (53.7%)	7 (6.5%)	22 (20.4%)	79 (73.1%)
Appropriate and fair selection of research participants	12 (11.2%)	23 (21.5%)	17 (15.9%)	55 (51.4%)	6 (5.6%)	18 (16.7%)	84 (77.8%)
Cultural sensitivity	12 (11.1%)	23 (21.3%)	22 (20.4%)	51 (47.2%)	25 (23.1%)	33 (30.6%)	50 (46.3%)
Accessibility to results	9 (8.4%)	26 (24.3%)	21 (19.6%)	51 (47.2%)	10 (9.3%)	25 (23.1%)	73 (67.6%)
Community engagement and involvement	8 (7.4%)	21 (19.4%)	20 (18.5%)	59 (54.6%)	21 (19.4%)	18 (16.7%)	69 (63.9%)
The role of regulatory frameworks	9 (8.3%)	21 (19.4%)	24 (22.2%)	54 (50%)	15 (13.9%)	30 (27.8%)	63 (58.3%)

Table 3 Participants confidence in addressing bioethical challenges in HIV research among special populations ($n = 108$)

Bioethical Challenge	Confidence in Addressing bioethical challenges (frequency/Percent)					*p*-value†
	Children/ Adolescents	Pregnant / Lactating Women	Older people	Key Populations	Sick & Hospitalized	
The process of informed consent/assent	66 (61.1%)	84 (77.8%)	88 (81.5%)	55 (50.9%)	70 (64.8%)	< 0.001
Principles of autonomy, beneficence* & justice	63 (58.3%)	79 (73.1%)	84 (77.8%)	55 (50.9%)	74 (68.5%)	< 0.001
Confidentiality & privacy	75 (69.4%)	87 (80.6%)	92 (85.2%)	56 (51.9%)	76 (70.4%)	< 0.001
Stigma & discrimination	52 (48.1%)	68 (63.0%)	69 (63.9%)	35 (32.4%)	60 (55.6%)	< 0.001
Incentives, undue influence & Coercion	49 (45.4%)	56 (51.9%)	62 (57.4%)	41 (38.0%)	50 (46.3%)	0.005
Role and responsibility of researchers	71 (65.7%)	78 (72.2%)	88 (81.5%)	58 (53.7%)	77 (71.3%)	< 0.001
Reporting Ethical Concerns	66 (61.1%)	71 (65.7%)	79 (73.1%)	45 (41.7%)	69 (63.9%)	< 0.001
Research on stored samples/data	54 (50.0%)	62 (57.4%)	65 (60.2%)	48 (44.4%)	59 (54.6%)	0.150
Assessing Risk and benefits	61 (56.5%)	62 (57.4%)	73 (67.6%)	49 (45.4%)	68 (63.0%)	0.015
Harm monitoring & Compensation for damages	40 (37.0%)	48 (44.4%)	57 (52.8%)	37 (34.3%)	51 (47.2%)	0.040
Relevance of research to local health needs	64 (59.3%)	75 (69.4%)	74 (68.5%)	45 (41.7%)	72 (66.7%)	< 0.001
Appropriate & fair selection of research participants	69 (63.9%)	74 (68.5%)	78 (72.2%)	46 (42.6%)	69 (63.9%)	< 0.001
Cultural sensitivity	47 (43.5%)	45 (41.7%)	56 (51.9%)	32 (29.6%)	47 (43.5%)	0.023
Accessibility to results	61 (56.5%)	66 (61.1%)	73 (67.6%)	45 (41.7%)	69 (63.9%)	0.001
The role of Community engagement/involvement	63 (58.3%)	58 (53.7%)	67 (62.0%)	40 (37.0%)	57 (52.8%)	0.003
The role of regulatory frameworks	58 (53.7%)	57 (52.8%)	65 (60.2%)	43 (39.8%)	61 (56.5%)	0.036

* *Beneficence: Refers to promoting the well-being of participants and, in this context, includes the principle of non-maleficence—ensuring that no harm is done*

† *p*-values generated using Pearson chi square

Most bio-ethical issues were significantly different across the groups (p-value < 0.05) with exception of research on stored samples/data that had a non-significant p-value 0.150

addressing ethical dilemmas in special circumstances (e.g., unconscious patients, notifiable diseases), genetic research ethics, paternal consent in pregnant women, data sharing, material transfer processes, post-trial access, and conduct of research in emergency settings. Specific issues regarding the GBMSM and transgender-related research were highlighted, specifically safeguarding human participants while adhering to legal frameworks and addressing data protection.

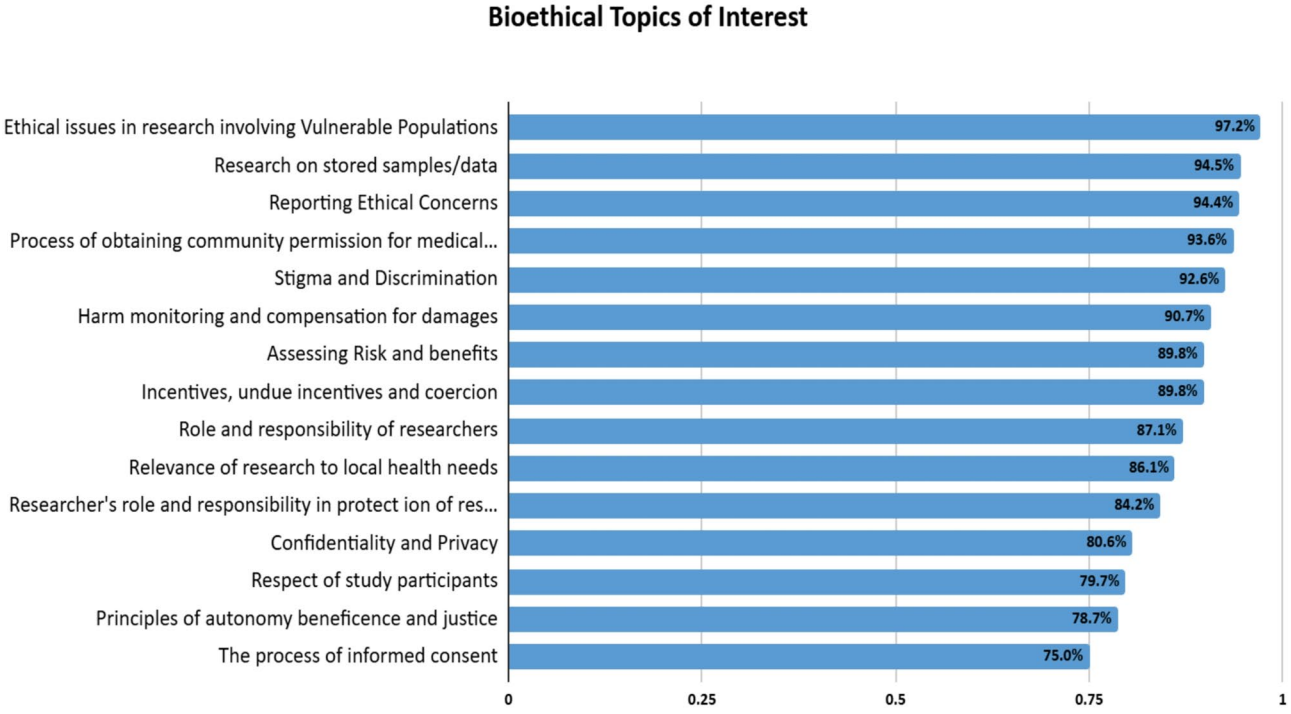


Fig. 1 Participants' preferred bioethical topics to be included in the curriculum ($n = 108$)

Table 4 Glossary of key bioethical principles

Term	Definition
Autonomy	The right of individuals to make informed, voluntary decisions about their participation in research, free from coercion or undue influence.
Beneficence	The ethical obligation to act in the best interest of participants by promoting their well-being and ensuring the research contributes to valuable outcomes.
Non-maleficence	Closely related to beneficence, it refers to the duty to do no harm and to minimize potential risks or adverse effects to research participants.
Justice	The principle of fairness in the selection of research participants and the equitable distribution of the benefits and burdens of research.

Discussion

This study assessed the bioethics training needs for trainees and junior researchers conducting research with PLWH. The findings revealed that trainees commonly faced various bioethical challenges, such as maintaining confidentiality and privacy, conducting informed consent processes, applying bioethical principles, engaging with communities, and selecting appropriate research participants. While trainees reported high confidence in addressing bioethical challenges in research with PLWH, their confidence levels were significantly lower and varied with different vulnerable populations, particularly key populations.

Note The bioethical principles referenced—autonomy, beneficence, and justice—are drawn from the foundational *Belmont Report* [23]. Although non-maleficence is considered a distinct principle in other frameworks [24], in this study it is conceptually integrated within beneficence, consistent with established interpretations in bioethics literature. This reflects the view that beneficence entails both the obligation to promote good and to avoid harm. For detailed definitions of each principle, see Table 4.

Although previous studies have explored the perceptions, knowledge, attitudes, and practice of trainees in medical and research ethics [17, 25–28], to the best of our knowledge, this is the first study focusing on vulnerable populations with or at risk of acquiring HIV in a country with a high HIV prevalence.

Despite the frequent engagement of trainees in research involving vulnerable populations significant gaps in bioethics training, knowledge and confidence in addressing complex ethical challenges, especially when working with key and marginalized populations were identified. This calls for an urgent need for targeted, context-specific training to strengthen ethical competence in conducting research among vulnerable groups.

While a significant majority of trainees reported having received some formal bioethics training and frequently encountering ethical challenges, their confidence was only moderate suggesting that the current training at Makerere University lacks contextual relevance, and practical application needed to address complex ethical challenges with vulnerable populations.

Higher confidence was reported in obtaining informed consent and maintaining confidentiality, however, confidence dropped for less frequent challenges, such as addressing stigma and discrimination, cultural sensitivity, harm monitoring and compensation, and reporting ethical concerns.

Participants reported high confidence in conducting research with older PLWH and pregnant/lactating women which may reflect more established ethical guidelines and experience in these areas. Lower confidence was reported for children and adolescents, key populations, and hospitalized patients. Conducting research with these groups may pose unique ethical challenges. For example, research with children and adolescents requires obtaining parental consent and participants' assent, and potential additional risks [29–31], while conducting research with sick and hospitalized patients presents unique challenges such as the determination of decision capacity, involvement of surrogate decision makers, risk versus benefit assessments, patient vulnerabilities, community engagement, and regulation of research [32, 33]. There is limited context-specific guidance on how to practically navigate these challenges [7].

In addition to the identified challenges, recent literature also suggests that some negative attitudes toward PLWH may stem not only from stigma or sociocultural biases, but also from perceptions of cognitive impairment. Neurocognitive challenges such as memory loss, reduced attention span, and executive dysfunction are particularly prevalent among some older PLWH and may hinder communication or informed consent processes [34–36]. When combined with lower literacy and socioeconomic disparities, these factors can reinforce implicit bias among healthcare workers or researchers, leading to exclusion or insufficient support for affected individuals. This highlights the importance of ethical training that incorporates an understanding of HIV-associated neurocognitive disorders, cultural sensitivity, and communication strategies to mitigate potential discrimination and uphold participant autonomy [35].

Of note research with key populations in Uganda and other African settings faces instead unique challenges, as persons and behaviors of GBMSM in many settings in SSA are highly stigmatized and even illegal [8, 10, 37] resulting in bioethical challenges when designing and implementing research studies. In Uganda a recent area of concern is the recently signed Anti-Homosexuality Act (AHA) which criminalizes same-sex behavior and may have a detrimental effect on research in HIV prevention, access to HIV testing and service delivery for key populations [38]. Also, a recent study [8] recommended a major focus on cultural sensitivity, community engagement, and reflexivity in research design and implementation for research among certain key populations in Uganda.

To situate our findings in a broader context, similar concerns about ethical preparedness have been reported in other cultural settings [34, 39], where studies among healthcare professionals and students emphasize the need for strong, context-specific ethical training. Recent literature further underscores the value of extending bioethics training beyond healthcare professionals to include patients and family members, especially in HIV research where stigma, cultural beliefs, and cognitive or literacy-related barriers may influence participation and ethical conduct [40, 41]. Involving these broader stakeholder groups can enhance ethical sensitivity, reduce stigma, and promote more inclusive and responsive research practices. Our study addresses this gap by identifying the tailored ethical training needs of trainees in HIV research withinSub-Saharan Africa. Future efforts should consider expanding training to engage patients, families, and communities as active partners in ethical research conduct.

For future bioethics training, in-person workshops emerged as the most favored training modality, followed by online courses and interactive case-based discussions. Participants expressed strong interest in a broad range of topics including those they had earlier on expressed confidence in addressing, reporting ethical concerns, community engagement in research, research on stored samples/data, harm monitoring and compensation, and risk-benefit assessment. Participants also suggested incorporating other topics such as genetic research ethics, ethical considerations in clinical trials for HIV care, paternal consent for pregnant women, data sharing, material transfer processes, and post-trial access.

We had a high non-response rate of 32.5%. However, since the online survey was distributed to all individuals of interest and the response rate was adequate (generally considered as at least 60% [42], the opinions of the trainees surveyed likely represent the ones of our population of interest [43]. Additionally, the reliance on a purely online survey introduced potential biases, as responses were subjective to participants' understanding of vulnerable populations and other bioethical concepts. Self-reported data is also inherently prone to recall bias and social desirability bias [44].

In conclusion, the findings highlight that trainees demonstrate a lack of confidence in addressing various bioethical challenges in research involving vulnerable populations of people living with HIV (PLWH), despite their frequent engagement in such research. These

findings are likely generalizable to similar academic and research institutions in East Africa that train students in HIV research, with potential applicability across sub-Saharan Africa. The insights gained have informed the development of a short bioethics training curriculum tailored to HIV research among vulnerable populations or those at risk of acquiring HIV. This training will target trainees and junior investigators at Makerere University, utilizing a mixed approach that includes lectures, real-world case scenarios, and prospective mentorship.

This study's strengths include a strong response rate, a systematic survey design, and a focus on an important yet underexplored area of HIV research ethics. However, the study had limitations, including potential biases from self-reported data and social desirability, varying interpretations of key terms, and the treatment of key populations as a homogeneous group rather than as distinct subgroups. Additionally, collapsing Likert-scale categories may have reduced the granularity of responses. While the list of bioethical issues covered was broad, it was not exhaustive, and some ethical dimensions may have been overlooked. Despite these limitations, the study provides a solid foundation for developing context-specific bioethics training in HIV research among vulnerable populations, and informing future research in similar settings.

Abbreviations

IDI	Infectious diseases institute
SoM	School of medicine
PLWH	People living with HIV
RLS	Resource limited settings
GBMSM	Gay, bisexual and other men who have sex with men
GCP	Good clinical practice
HSP	Human subject protection
REC	Research ethics committee
HIV	Human immunodeficiency virus
UNCST	Uganda national council of science and technology
Mak-IR	Makerere university institutional repository

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12910-025-01244-y.

Supplementary Material 1

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Author contributions

J.N participated in writing the protocol, acquiring regulatory approvals, data collection and analysis, drafting, revising and finalization of the manuscript. S.O conceptualized the idea, participated in protocol writing, revised and finalized the manuscript. G.B performed data analysis, revised and finalized the manuscript. P.B.K conceptualized the idea, participated in protocol writing. B.C conceptualized the idea, participated in protocol writing, acquired regulatory approvals, gave oversight to the study implementation, revised and finalized the manuscript.

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Data availability

All data supporting the findings of this study are available within the paper and its Supplementary Information.

Declarations

Ethics approval and consent to participate

This study was conducted in accordance with the ethical principles outlined in the Declaration of Helsinki. Ethical approval was obtained from the Infectious Diseases Research and Ethics Committee (reference number: #REF IDI-REC 2023-078), and from Uganda National Council for Science and Technology (UNCST, reference number: HS3771ES). Informed consent was obtained from all participants. Participants received detailed information about the survey through an electronic consent form (as approved by the REC) embedded within the survey link. Those who voluntarily chose to participate indicated their consent by selecting "I agree to participate" before proceeding to the survey. The e-consent served as an acknowledgment of willingness to participate rather than a full signature.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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References

1. Gahagan J, Sweeney E, Worthington C, Perry D, Satzinger F, Rogers E. Ethics issues for HIV/AIDS researchers in international settings - perspectives from the Canadian experience. Int J Infect Dis. 2008;12(6):569–72.
2. Gillette E, Nyandiko W, Chory A, Scanlon M, Aluoch J, Choudhury N, et al. Ethical considerations for engaging children and adolescents living with HIV in research in African countries: A systematic review. J Empir Res Hum Res Ethics: JERHRE. 2023;18(5):346–62.
3. Bekker LG. HIV control in young key populations in Africa. Lancet Child Adolesc Health. 2019;3(7):442–4.
4. Gonzalez-Duarte A, Zambrano-Gonzalez E, Medina-Franco H, Alberu-Gomez J, Durand-Carbajal M, Hinojosa CA, et al. Ii. The research ethics involving vulnerable groups. Rev Invest Clin. 2019;71(4):217–25.
5. Sengupta S, Lo B, Strauss RP, Eron J, Gifford AL. How researchers define vulnerable populations in HIV/AIDS clinical trials. AIDS Behav. 2010;14(6):1313–9.
6. Flores L, Young SD. Ethical perspectives in using Technology-Enabled research for key HIV populations in Rights-Constrained settings. Curr HIV/AIDS Rep. 2023;20(3):148–59.
7. Dube K, Kanazawa J, Taylor J, Dee L, Jones N, Roebuck C, et al. Ethics of HIV cure research: an unfinished agenda. BMC Med Ethics. 2021;22(1):83.
8. Muwanguzi PA, Nabunya R, Ngabirano TD. Navigating HIV research among criminalized gender minority populations in uganda: qualitative insights and lessons learned from novice researchers. Int J Equity Health. 2024;23(1):201.
9. Sugarman J, Rose SM, Metzger D. Ethical issues in HIV prevention research with people who inject drugs. Clin Trials. 2014;11(2):239–45.
10. Boakye DS, Kumah E, Adjorlolo S. The fight for an AIDS-Free world: confronting the stigma, reaching the marginalized. Annals Global Health. 2024;90(1).
11. Shagi C, Vallely A, Kasindi S, Chiduo B, Desmond N, Soteli S, et al. A model for community representation and participation in HIV prevention trials

among women who engage in transactional sex in Africa. AIDS Care. 2008;20(9):1039–49.
12. Couper I, Ray S, Blaauw D, Ng'wena G, Muchiri L, Oyungu E, et al. Curriculum and training needs of mid-level health workers in africa: a situational review from kenya, nigeria, South Africa and Uganda. BMC Health Serv Res. 2018;18(1):553.
13. Ateudjieu J, Williams J, Hirtle M, Baume C, Ikingura J, Niaré A, et al. Training needs assessment in research ethics evaluation among research ethics committee members in three African countries: cameroon, Mali and Tanzania. Developing World Bioeth. 2010;10(2):88–98.
14. Tchio-Nighie KH, Bekolo CE, Kiadjieu Dieumo FF, Kouanfack C, Ateudjieu J. Research ethics in training curricula of Cameroon health training institutions: A Cross-Sectional study. Cureus. 2024;16(5):e59567.
15. Barman B, Srivastava TK, Sarma A, Nath CK. Effectiveness of formal training in bioethics of 3(rd) semester undergraduate medical students in recognizing bioethical issues and principles in patient care. J Family Med Prim Care. 2020;9(6):2871–6.
16. Griggins C, Simon C, Nakwagala FN, Pentz RD. Bioethics training in uganda: report on research and clinical ethics workshops. HEC Forum: Interdisciplinary J Hospitals' Ethical Legal Issues. 2011;23(1):43–56.
17. Chongwe G, Sikateyo B, Kampata L, Ali J, Hallez K, Hyder AA, et al. Assessing training needs in health research ethics: a case study from the university of Zambia school of medicine. Glob Bioeth. 2020;31(1):155–63.
18. Eldridge GD, Robinson RV, Corey S, Brems C, Johnson ME. Ethical challenges in conducting HIV/AIDS research in correctional settings. J Correct Health Care. 2012;18(4):309–18.
19. Hlongwa P. Current ethical issues in HIV/AIDS research and HIV/AIDS care. Oral Dis. 2016;22(Suppl 1):61–5.
20. Singh Z, Banerjee A, HIV / AIDS. Social and ethical issues. Medical journal. Armed Forces India. 2004;60(2):107–8.
21. Van Hoof W, Meesters K, Dossche L, Christiaens D, De Bruyne P, Vande Walle J. Ethical considerations of researchers conducting pediatric clinical drug trials: a qualitative survey in two Belgian university children's hospitals. Eur J Pediatrics. 2018;177(7):1003–8.
22. Sullivan GM, Artino AR Jr. Analyzing and interpreting data from likert-type scales. J Graduate Med Educ. 2013;5(4):541–2.
23. Department of Health E, Welfare, National Commission for the Protection of Human Subjects of B, Behavioral R. The Belmont report. Ethical principles and guidelines for the protection of human subjects of research. J Am Coll Dent. 2014;81(3):4–13.
24. Beauchamp TL, Childress JF. Principles of biomedical ethics. Oxford University Press; 1979.
25. Selvaraj K, Sudhir B, Nelson BTSB, editors. Perception of interns and postgraduates towards Medical Ethics Education2013.
26. Grosek Š, Rigler P, Podbregar M, Erčulj VJBME. Knowledge of and attitudes towards medical research ethics among first year doctoral students in Slovenia at the faculty of medicine. Univ Ljubljana. 2023;23.
27. Munung NS, Tangwa GB, Che CP, Vidal L, Ouwe-Missi-Oukem-Boyer O. Are students kidding with health research ethics? The case of HIV/AIDS research in Cameroon. BMC Med Ethics. 2012;13:12.
28. Faihs L, Neumann-Opitz C, Kainberger F, Druml C. Ethics teaching in medical school: the perception of medical students. Wien Klin Wochenschr. 2024;136(5–6):129–36.
29. Crane S, Broome ME. Understanding ethical issues of research participation from the perspective of participating children and adolescents: A systematic review. Worldviews evidence-based Nurs. 2017;14(3):200–9.
30. Shah SK, Essack Z, Byron K, Slack C, Reirden D, van Rooyen H, et al. Adolescent barriers to HIV prevention research: are parental consent requirements the biggest obstacle?? J Adolesc Health. 2020;67(4):495–501.
31. Loue S, Pike EC. HIV research with children. Case studies in ethics and HIV research. Boston, MA: Springer US; 2007. pp. 205–20.
32. Ecarnot F, Quenot JP, Besch G, Piton G. Ethical challenges involved in obtaining consent for research from patients hospitalized in the intensive care unit. Annals Translational Med. 2017;5(Suppl 4):S41.
33. Hirner S, Saunders C, Stassen W. The ethical considerations for emergency care research in low- and middle-income countries: A scoping review of the published literature. Afr J Emerg Medicine: Revue Africaine De La Med D'urgence. 2022;12(1):71–6.
34. Giannouli V. What do health care professionals, students, and laypeople in Greece believe about informed consent for research on medical practices? Unleashing pandora's box. Porto Biomed J. 2023;8(6):e236.
35. Tragantzopoulou P, Giannouli, VJPoPitsC. A review of the literature on HIV and neuropsychological functioning in older adults. Is More Res Needed? 2023;17(1):47–56.
36. Giannouli V, Tsolaki M. Elder financial abuse and the COVID-19 pandemic: A call to action through training programmes? Psychiatrike = Psychiatriki. 2022;33(4):333–4.
37. Epprecht M. Sexual minorities, human rights and public health strategies in Africa. Afr Affairs. 2012;111(443):223–43.
38. Nakkazi E. The threat of the Anti-Homsexuality act in Uganda. Lancet Infect Dis. 2023;23(6):662.
39. Alkabba AF, Hussein GM, Albar AA, Bahnassy AA, Qadi M. The major medical ethical challenges facing the public and healthcare providers in Saudi Arabia. J Fam Commun Med. 2012;19(1):1–6.
40. Mohammadifirouzeh M, Oh KM, Tanner S. HIV stigma reduction interventions among health care providers and students in different countries: A systematic review. Curr HIV Res. 2022;20(1):20–31.
41. Machowska A, Bamboria BL, Bercan C, Sharma M. Impact of 'HIV-related stigma-reduction workshops' on knowledge and attitude of healthcare providers and students in central india: a pre-test and post-test intervention study. BMJ Open. 2020;10(4):e033612.
42. Andrade C. The limitations of online surveys. Indian J Psychol Med. 2020;42(6):575–6.
43. Windle J, Rolfe JJEA. Comparing responses from internet and Paper-Based collection methods in more complex stated. Preference Environ Valuat Surv. 2011;41:83–97.
44. Althubaiti A. Information bias in health research: definition, pitfalls, and adjustment methods. J Multidisciplinary Healthc. 2016;9:211–7.

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