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Ethical Perspectives in Using Technology-Enabled Research for Key HIV Populations in Rights-Constrained Settings

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Abstract

Purpose of Review People who use illicit drug substances (e.g., heroin) and sex workers are vulnerable to acquiring HIV. Due to the criminalization of illicit drug substances and sex work in many countries, these populations often reside in rights-constrained settings where their well-being, freedom, and access to HIV prevention and care services may be compromised due to legal prosecutions and societal stigma.

Recent Findings This study conducted a literature review on papers that evaluated a combination of the following three components: ethics, technology-based research, and populations who use drug substances and/or sex workers. We explored research on these ethical perspectives from both key populations and researchers.

Summary Findings revealed potential risks in data security and possible harmful implications of compromised data within these rights-constrained settings. Best practices were explored within the literature to identify potential methods for addressing these ethical concerns and improving HIV prevention and care.

Keywords Ethics · Social media · Apps · Rights-constrained · Sex work · Illicit substance

Introduction

Human immunodeficiency virus (HIV) continues to be a significant global health problem, especially among populations living in rights-constrained settings, such as sex workers and people who use drug substances. Approximately 1.5 million individuals became infected with HIV in 2020 [1]. Factors such as illicit substance use (e.g., heroin) and substance misuse (e.g., prescription opioid misuse) increase the likelihood of acquiring HIV. Roughly 1 in 10 HIV diagnoses can be attributed to injection drug use [2]. Opioid misuse has been associated with engagement in condomless sex, also contributing to an increased chance of acquiring HIV [3]. Sex workers are vulnerable to HIV exposure due to socioeconomic factors that may contribute to not utilizing protection during sexual intercourse [4, 5]. People who use drug substances and sex workers are often overlapping populations. For example, research within Southeast Asia and East Europe has found high proportions of sex workers who inject drugs [6]. Taken together, it is important to study these key populations both individually and overlapping to improve HIV prevention and care.

Rights-constrained settings impose additional barriers among people who consume drug substances for non-medical use and sex workers due to the potential negative impact of surveillance and criminalization. For instance, illicit substance use, such as heroin and methamphetamine use, is criminalized in many parts of the world and may lead to long-term harm to individuals and communities [7]. Heroin and crack cocaine are both illegal within the USA, with heroin classified as a Schedule 1 substance and crack cocaine as a Schedule II substance under the Controlled Substances Act [8, 9]. Use and distribution of either of these substances are a violation of the Controlled Substances Act and prosecuted by the Department of Justice [10]. Due to this criminalization, stigma is heightened within society, creating negative or discriminatory attitudes towards people who use illicit drug substances [11]. People who use illicit drug substances may be deterred from seeking health services, such as HIV prevention and care, due to drug law enforcement practices [12].

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Criminalization is also a leading contributor to health disparities among sex workers [13]. Research has supported that sex workers are one of the most marginalized populations in the world, facing dangers such as homicide, violence, and harassment [14]. Similar to groups who utilize illicit drug substances, studies argue that the prosecution of sex workers leads to increased violence and stigma towards these individuals [15, 16]. Criminalization may also impact sex workers access to healthcare services that could provide HIV preventative services or treatment [13]. Rights violations may also extend into housing, security, and privacy and are a direct impact of criminalization and stigma.

Technology may be a promising tool for improving HIV prevention among people who use drug substances and sex workers who are living in rights-constrained settings [17, 18]. More broadly across populations affected by HIV, social media technologies have shown promising capabilities among men who have sex with men (MSM). For instance, the Harnessing Online Peer Education (HOPE) social media interventions have suggested an increase in HIV testing among Peruvian MSM in a randomized controlled trial [19]. Similarly, benefits have also been observed among African American and Latino MSM on Facebook [20, 21]. Online intervention studies utilizing social media have also shown promise for reducing prescription opioid misuse risk factors [22]. Furthermore, the implementation of mobile health (mHealth) applications for increasing pre-exposure prophylaxis (PrEP) uptake have also reflected positive findings on technologies' effectiveness in aiding behavior change [23]. mHealth tools to address HIV prevention among MSM have already proven to be effective and feasible [24].

However, there are several potential ethical issues that arise when implementing HIV prevention strategies among people who use illicit substances and/or sex workers, especially among individuals living in rights-controlled settings [25]. Information that participants provide in research on their substance use, or engagement in sex work, may be utilized against them in legal pursuits if data is released to third parties, government entities, or other institutions. The consequences of such third parties being privy to these data may hold long-term ramifications for these individuals. Hence, privacy and confidentiality are of the utmost importance to prevent harm to participants. In this study, we conduct a literature review on publications that evaluate ethical components (e.g., acceptability, informed consent, risks of harm) in the use of technology to address populations within rights-constrained environments. This study focuses on people who use illicit substances and sex workers because those behaviors are often restricted and/or illegal across the world, allowing us to investigate the ethical issues that may arise among these populations within these settings.

Methods

We conducted a systematic literature search for papers published between 2007 and 2022 worldwide on the National Library of Medicine's PubMed on November 28, 2022. Our database search comprised the following three subject criteria: (1) ethical considerations, (2) technological elements, and (3) rights-constrained groups related to substance use or sex work. Within PubMed, we utilized the advanced search query option to apply Boolean logic and extract articles containing our criteria. Keywords of interest related to ethical considerations were extracted from principles in the Belmont Report [26]. Our search criteria for technological elements included any use of technology within the intervention or methods (e.g., data collection) of a study. Keywords of interest for illicit substances were identified by the authors based on the United States Drug Enforcement Agency (DEA) Schedule I substances (e.g., heroin) that are illicit within the USA [27] and not currently accepted for medical use. Inclusion of Schedule II substances (e.g., opioids, cocaine) were also included due to their high potential for abuse [27] and a recent link of opioids to an HIV outbreak according to the Center for Disease Control and Prevention (CDC) [28]. The incorporation of Schedule II substances within the search query were to capture literature related to non-medical use of substances. We utilized a combination of the search terms outlined in Table 1.

Literature Criteria

Priority populations related to substance use or sex work are described in Table 2. Our search criteria included literature that studied priority populations in countries where sex work or the substances utilized are illicit/or criminalized. Non-medical use of opioids was included due to stigmatization, which may create a rights-constrained environment, and increase vulnerability to HIV [3].

Inclusion criteria for manuscripts were based on the classifications outlined in Table 3.

The records identified through database searching were 217 articles from PubMed. The search was led by the first author (LF).

Exclusion Criteria

To narrow down our search, a manual review of literature was conducted by first author (LF) to identify manuscripts that discussed ethical perspectives. Manuscript abstracts were reviewed for relevance and ethical perspectives related to the acceptability of technology, informed consent, privacy, or confidentiality issues were marked as relevant. Due

Table 1 Search query keywords

Subject criteria (1) ethical considerations	
Ethics	*Ethics OR informed consent OR privacy OR confidential OR fairness OR benefits OR benefits and risk OR subject selection OR respects for persons OR beneficence OR justice*
Subject criteria (2) technological elements	
Technology	*social media OR internet OR technology OR mobile apps OR MHealth OR eHealth OR big data OR digital health*
Subject criteria (3) rights-constrained groups related to substance use or sex work	
Schedule I substances	*illicit OR drug OR heroin OR meth OR ecstasy OR LSD OR methaqualone OR peyote OR marijuana*
Schedule II substances	*opioid OR crack/cocaine OR Vicodin OR methamphetamine OR methadone OR hydromorphone OR meperidine OR oxycodone OR fentanyl OR Dexedrine OR Adderall OR Ritalin*
Sex work	*sex work OR transactional sex OR exchange sex*

Table 2 Populations of interest

	Description	Substance
Rights-constrained population 1 (P1)	- Person with substance use disorder (non-medical use of a drug) - Person with dependence on an illicit drug substance - People who consume drugs substances for non-medical use (recreational)	- Use of heroin, meth, crack/cocaine - Non-medical use of an opioid
Rights-constrained population 2 (P2)	- Individuals engaged in sale of sexual services - Sex worker	

Table 3 Classification criteria

Publication year	2007–2022
Population of interest	Sex workers and people who use drugs
Rights-constrained setting	Use of substance or engagement in sex work is illegal within the targeted location/or country of interest. Non-medical use of opioids or Schedule II drugs is stigmatized or illegal within location of interest
Keywords of interest in title/abstract	Title or abstract of manuscript must contain one keyword from each of the three subject criteria outlined in Table 1
Technology-enabled component	Any use of technology elements within the intervention or methods (e.g., data collection) of a study
Publication type	Journal article

to gaps in literature that arose with this approach, we also reviewed references within articles to identify additional papers that met our search criteria. Literature discussing harm reduction in relation to the harms that exist within rights-constrained setting and their impact on populations were included. The literature strictly discussing harm reduction in relation to drug effects (e.g., overdose, relapse) was excluded. However, literature that evaluated both types of harms was included. Manuscripts that referenced technology broadly as an advancement in science, such as novel vaccines or medical treatments, were excluded. Mentions of technology involving computer-based processes or electronic devices were included.

Ultimately, the articles selected for this literature review were composed of studies in over 7 different countries with varying laws and regulations. Our literature review focused on the following criminalized behaviors: illicit drug usage (i.e., heroin, cocaine, crack) and sex work, as these characteristics are confined to rights-constrained settings. To address varying legal stances across countries, our definition of a rights-constrained setting also encompassed stigmatization and its effects on human rights among the two populations of interest. The literature regarding individuals who misuse Schedule II substances, whether illegal or not within the region of the study, was included. The literature on sex work, whether sex work is illegal or not in the study region, was included due to the population's vulnerability to human rights violations and stigmatization.

These settings increase individuals' chances of acquiring HIV and hold unique consequences that prevent fair access to public health services [3].

Results

We found 23 articles focused on people who use drugs and 5 applicable to research on sex workers. To evaluate the unique ethical considerations that arise within each subgroup, we broke down the papers into the following two categories: people who use drugs and sex workers. Table 4 outlines the study types, technologies implemented, and ethical concerns addressed throughout each paper related to persons who are dependent on drug substances. Study types classified as research reports were case reports that reported on the population of interest through either qualitative or quantitative methods. Cross-sectional observational reports assessed the prevalence of an outcome at a given point in time.

Table 5 outlines the study types, technologies implemented, and ethical concerns addressed throughout each paper related to sex workers.

Non-Medical Substance Use

We identified 23 papers related to the ethics of utilizing technology among people who are dependent on drug substances [29••, 30••, 31••, 32••, 33••, 34••, 35••, 36••, 37••, 38••, 39••, 40••, 41••, 42••, 43••, 44••, 45••, 46••, 47••]. The first paper, "Ethical considerations and potential threats to validity for three methods commonly used to collect geographical information in studies among people who use drugs" by Rudolph et al. conducted interviews with residents who reported recent illicit drug use (e.g., heroin, crack, or cocaine) to explore their level of comfort with three methods for collecting geographic information, surveys that collected self-reported addresses, surveys that used web-based maps to find/confirm locations, and geographical monetary assessments (GMA) [48••]. The authors recruited 15 Baltimore residents for semi-structured in-person interviews. The criteria for participating in the study included self-reported heroin, crack, or cocaine use within the last 6 months. Most participants were living with HIV and/or black, indigenous, person of color (BIPOC). Furthermore, 87% of participants had previously been arrested for a drug-related offense. Through semi-structures interviews, the authors evaluated participant perspectives on the use of research surveys that collect geographical information through web-based maps. The author findings revealed participant concerns on providing exact addresses due to their engagement in illicit/stigmatized behaviors. Participants expressed discomfort in carrying study phones and being tracked, with many being unwilling to comply with this study procedure and taking measures to disable phones or leave them at home. The authors findings substantiated a call for more discussion on the ethical protocols of research involving participants who engage in illicit or stigmatized behaviors.

"A qualitative study of big data and the opioid epidemic: recommendations for data governance" by Evans et al. conducted interviews with big data researchers to identify ethical concerns in utilizing big data to address the opioid epidemic [49••]. The Public Health Data (PHD) Warehouse is an online health surveillance platform for the state of Massachusetts that provides access to deidentified data on opioid usage for research purposes. Researchers who had previously utilized the PHD Warehouse were recruited for semi-structured interviews and focus groups. This included biomedical researchers, epidemiologists, and data scientists. Additionally, big data gatekeepers (e.g., data managers) were recruited and patient advocates who were recruited from community forums were also included within the study. Interviews were conducted in-person and through teleconference. The following topics were the primary focus of these interviews: protect and respect patients, ensure justice, and foster public trust. Some of the questions that researchers were encouraged to evaluate were "How do we ensure that the potential harms of big data are outweighed by its benefits?" and "How do we ensure that big data does not further privilege certain groups or widen existing disparities?" Findings suggested potential privacy infringement dangers due to increased profiling and surveillance capabilities. Despite the aggregation and anonymization of big data, authors suggested it may hold potential to increase stigmatization and discrimination of the population due to findings derived from it. Within the topic of "protect and respect patients and society," participants raised concerns that big data on opioid usage could be misused by government entities and institutions. The fear of prosecution and incarceration, despite data anonymization, remained a prevalent concern among participants. Furthermore, the fear of long-term individual-level harm such as denial of health insurance, welfare, and employment were also discussed. Along with highlighting ethical concerns, this study presented strategies that could be implemented to address ethical issues. The creation of community advisory boards (CABs) that directly involve individuals with opioid use disorder (OUD) within research was presented as a potential solution to identifying harms and benefits. Additionally, shared big data governance systems may hold potential for ensuring individuals with OUD are protected from harms. Authors expressed limitations within CABs and co-governance in terms of their feasibility but emphasized their potential in an ideal setting. This paper called for a refocus on ethical concerns so that the benefits of using big data for opioid research outweigh the potential harm to rights-constrained groups.

The publication by Miller and Sønderlund conducted a systematic review of internet-based strategies utilized to research populations who use illicit drugs. The authors sourced their articles globally covering countries where

Table 4 Characteristics of research studies observed focused on substance use ($N=23$)

Author	Study type	Sample size	Location	Technology	Ethical concerns
Rudolph et al., 2016	Research report	15 HIV-positive individuals and/or black, indigenous, and people of color (BIPOC) who have self-reported illicit drug use (e.g., heroin, crack, or cocaine use). Data were obtained through semi-structured qualitative interviews	Baltimore	Web-based mapping, collection of geographical data through mobile devices	- Concerns of carrying/safeguarding study phones - Comfort with providing location - Burdens - Confidentiality - Anticipated harms
Evans et al., 2020	Research report	39 researchers, gatekeepers, and advocates who have utilized the online Public Health Data (PHD) Warehouse. Included biomedical researchers, epidemiologists, and data scientists. Data were obtained through semi-structured qualitative interviews	Massachusetts	Big data	- Respect (individual-level harm) - Equity (exacerbate social inequalities) - Trust - Ensuring justice
Miller & Sønderlund, 2010	Literature review	46 publications that utilized the internet as a research tool for substance use analyses	N/A	Internet recruitment methods	- Level of intrusiveness - Ethically problematic strategy of spamming
Capon et al., 2016	Literature review	33 articles which involved mHealth apps for research on substance abuse of illicit drugs or addiction	N/A	Smartphones and mhealth applications	- Privacy - Data storage and transfer - Third-party access - User anonymity - Informed consent - Equal access to mHealth technology
Germain et al., 2018	Viewpoint	Persons with dependence on drug substances	UK	Online research	- Protection from harm
Tofighi et al., 2017	Literature review	Persons with dependence on an illicit drug substance	N/A	Mobile phone interventions	- Acceptability by evaluating participant satisfaction
Butler et al., 2017	Viewpoint	Persons with dependence on an illicit drug substance	N/A	Electronic health records, big data	- Privacy concerns due to centralized data and storing “big data” - Stigma concerns
Pessar et al., 2021	Cross-sectional observational study	Evaluation of federal and state governments across 50 US states	USA	Telehealth	- Privacy laws for health data that vary by state
van Draanen et al., 2022	Viewpoint	Persons with dependence on an illicit drug substance	Canada	Passive surveillance technology	- Privacy - Informed consent - Legal ramifications

Table 4 (continued)

Author	Study type	Sample size	Location	Technology	Ethical concerns
Gonzales et al., 2021	Literature review	104 articles related to longitudinal health records, data sharing, and research applications for blockchain	USA	Blockchain	- Acceptability - Confidentiality in relation to blockchain
Brown et al., 2020	Research report	20 participants who self-reported cocaine use. Data were obtained through focus groups	USA	mHealth	- Acceptability - Privacy concerns such as collection of demographic information
Kim et al., 2020	Critical review	Persons with dependence on an illicit drug substance	USA	Social media big data	- Privacy of sensitive data and reidentified subjects - Ethical guidelines
Proctor et al., 2022	Research report	10 patients with dependence on drug substance for non-medical use. Data were collected through in-depth qualitative interviews	USA	Reward-based mobile app, video conference interviews	- Acceptability of application
Tsang et al., 2021	Research report	486 persons who consume drugs for non-medical use. Data were obtained through a survey	USA, Canada	Mobile phones	- Acceptability - Privacy - Fear of stigma
Ti et al., 2021	Commentary	Persons who consume drugs for non-medical use	North America	Artificial intelligence	- Informed consent
Pasipanodya et al., 2020	Research report	13 Black and Hispanic men who have sex with men living with HIV who use methamphetamine. Data were obtained through focus groups	USA	Smartphones or mobile technologies	- Risk of harm - Legal consequences - Confidentiality
Varshney et al., 2022	Cross-sectional observational report	Identified 153 opioid applications	N/A	mHealth apps	- Security and privacy such as adherence to HIPAA guidelines, privacy provisions
Roth et al., 2017	Research report	38 individuals who inject drugs. Data were collected through qualitative interviews	San Diego, California, and Philadelphia	Ecological momentary assessment via mobile technology	- Potential harms and legal risks - Data security
Langdon et al., 2022	Research report	8 participants with opioid use disorder. Data were collected through qualitative in-depth interviews	RI, USA	Digital health intervention	- Acceptability using thematic and content analysis
Aronson et al., 2020	Research report	16 individuals who have experience in harm reduction. Data were collected through qualitative interviews	USA	Technology-based tools and messaging	- Acceptability - Privacy - Benefits
Young et al., 2017	Research report	Persons with dependence on opioids. Data were collected through qualitative interviews	USA	Online peer lead intervention	- Acceptability based on usage patterns

Table 4 (continued)

Author	Study type	Sample size	Location	Technology	Ethical concerns
Hsu et al., 2022	Literature review	8 articles on mobile phone ownership among individuals with dependence on drugs	N/A	Mobile applications	- Acceptability - Privacy concerns (e.g., app tracking participant locations)
Corneli et al., 2022	Research report	11 people who inject drugs. Data were collected through qualitative interviews	NC, USA	Telemedicine	- Acceptability - Privacy in phone sharing

sex work is both legal and illegal such as the USA, Brazil, Canada, and Japan [50–55]. However, this paper did not directly aim to address ethical concerns. We included this paper within our works as many of the disadvantages that were highlighted such as newsgroups, spamming, and online advertising included ethical concerns. The authors highlighted concerns in utilizing newsgroups and spamming as sampling methods, hence briefly touching on the underlying concept of ethics that we aim to spotlight. It is important to note that ethical considerations may also be contended by evaluating the acceptability of technologies. Acceptability may be evaluated by measuring the population adherences to technology and/or their comfortability with the technology's efforts to preserve participant privacy. In the Langdon et al. study, the acceptability of text message delivered interventions among people with opioid use disorder were evaluated through interviews that inquired about privacy and its impact on intervention engagement. One participant expressed that their information should not be shared with law enforcement, and another expressed that the data should be anonymized. Literature, such as the Aronson et al. and Hsu et al. manuscript, also evaluated acceptability through a privacy and confidentiality lens.

In the Capon et al. article, "Realizing the technological promise of smartphones in addiction research and treatment: an ethical review," the authors addressed how technical methodologies such as data storage and transfer may pose risks to participants [56••]. The authors conducted an ethical review of the implementation of smartphones in addiction research by identifying 33 studies involving smartphones for research and treatment on substance abuse ranging from tobacco, alcohol, heroin, and cocaine. We chose to focus on the components related to illicit substances: heroin and cocaine. These studies were conducted within the USA. Publications on cocaine usage involved black, indigenous, or people of color as participants. Privacy was discussed as a focal point of ethical concern as criminalized behaviors and the location in which these behaviors are conducted may place participants at risk of prosecution. The authors made the claim that it is an ethical obligation for researchers to be proactive in protecting data from third parties due to its sensitive nature and the potential consequences of its release. Furthermore, the authors highlighted concerns on the lack of information regarding data storage presented within these studies that collect data on illegal behaviors. The security level of this data was unknown and required addressing. Within the Capon et al. article, third-party data access was discussed from a legal perspective. The authors outlined situations where information privacy may be compromised. For instance, if researchers are presented with a subpoena, they are legally obligated to provide information on participants which may include drug-related data. Law enforcement may also require participants who they suspect are engaging in illegal behaviors to turn in their smartphone device data. If involved in research, device

Table 5 Characteristics of research studies observed focused on sex workers ($N=5$)

Author	Study type	Sample size	Location	Technology	Ethical concerns
You et al., 2020	Research report	22 cisgender sex workers. Data were collected through qualitative interviews	South Africa	Mobile phones and advanced technologies (e.g., biometric identification, social media, chatbots)	- Privacy, such as inconsistent phone ownership - Threats to security
Thomas et al., 2017	Research report	40 male sex workers. Data were collected through qualitative interviews	Chennai, India	Mobile phone technology	- Acceptability among population - Privacy and confidentiality
Brody et al., 2017	Observational research report	15 sex workers	Cambodia	Mobile phone	- Privacy assurance
Fisher, 2014	Literature review	Female sex workers	USA, India, Philippines	Online recruitment or methods	- Potential research harms - Recruitment incentives - Consent comprehension
Peters et al., 2022	Research report	20 Male sex workers. Data were collected through qualitative interviews	Netherlands	Online health services	- Acceptability based on participant utilization

records may contain data on illegal behaviors and serve as proof of engagement in them.

Sex Work

We identified 5 papers related to the utilization of technology in research that engages sex workers as participants [57••, 58••, 59••, 60••]. We identified two manuscripts, the Thomas et al. and Peters et al. articles that evaluated the acceptability of technologies through an ethical lens. In the Thomas et al. article, the authors evaluated the acceptability of mobile phone interventions among sex workers. Participants expressed concerns on confidentiality and privacy as barriers to these interventions. Furthermore, participants expressed fear of social harm if information about their engagement in sex work were to be revealed to family members. Fear of social harm was listed as a barrier to participation. In the Peters et al. article, concerns on confidentiality and privacy were also barriers to participation. Stigma and disclosure concerns impacted the acceptability of technologies and willingness to seek sexual healthcare services. The authors addressed these ethical concerns by emphasizing the importance of providers building trust among participants through providing direct telephone numbers and/or tailored information.

Discussion

People who misuse drug substances and sex workers are populations vulnerable to HIV and face unique challenges due to living in rights-constrained settings. Illicit substance use behaviors are criminalized within rights-constrained settings and impose long-term consequences on the well-being and freedom of these individuals [61••]. Technology-enabled research, through platforms such as social media and mobile applications, bring forth additional risks to data security. Jointly, research on key populations and technology-enabled tools create unique ethical challenges that require addressing. Concerns regarding privacy and confidentiality of data are heightened when data may reveal engagement in illicit behaviors that are criminalized. Methods of protecting data from third parties such as government entities and law enforcement are important to address. Consequences of not protecting this data may involve criminal prosecution and hold long-term implications (e.g., incarceration, denial of healthcare services) for these key populations. Hence, data security and limiting third-party access to research data requires constant evaluation and improvement. This evaluation of ethics may help inform law reforms and protect key populations susceptible to the harms of their rights-constrained settings. One study even suggests that decriminalizing sex work may lower HIV acquisition by up to 46% over the next 10 years [16].

According to a study by John Hopkins Bloomberg School of Public Health, research also suggests that criminalizing drug use worsens health outcomes. Societal stigma surrounding criminalized behaviors may heighten the harmful effects of compromised data. Furthermore, stigma may lead to physical dangers and social isolation. Implementation of ethical guidelines and procedures may be an effective method of addressing such concerns [49••].

Table 6 Main takeaways on best practices

- Updating and evaluating data security processes for safeguarding sensitive information
- Creating trust among populations through communication
- Transparency with participants regarding risks and safety measures in-place
- Importance of researchers to remain up to date with local laws and their implications

Best Practices

To better understand and address potential ethical concerns in this area, we believe that it is important to improve communication between researchers and people who use drug substances and sex workers to understand how to best safeguard their data and ensure confidentiality. The development of strict data storage and access protocols may be an approach to safeguarding and handling technology-enabled sensitive data [26]. Informing participants of these safety measures may help address concerns related to privacy and confidentiality. Following principles, such as those in the Belmont Report, and identifying unique barriers to informed consent or beneficence among sex workers or individuals who use drug substances may help address ethical issues unique to these populations [26]. It is through open communication with these populations that we may learn best practices for keeping these individuals safe from third parties and the potential harm that may come with them. Furthermore, we urge researchers to learn about their local laws and the implications that criminalization may have on their participants' rights. Rights-constrained settings pose unique challenges that may often remain overlooked by study teams, leaving participants at risk of incarceration, discrimination, or harassment, etc. This literature review is intended to highlight the ethical considerations that arise in technology-enabled studies involving marginalized populations and the implications of their rights-constrained settings. Table 6 details high-level takeaways for researchers to consider when developing studies.

Limitations

There are several limitations within the scope of this literature review, most broadly being that this was not a purely systematic review. Some papers that did not meet inclusion criteria were included because we believe that they have relevance to the topic even if they did not explicitly meet all 3 search term criteria in the inclusion criteria. The first of which is that the Miller and Sønderlund literature review on studies involving people who use illicit drugs did not focus on ethical concerns and primarily evaluated methods [62••]. We chose to highlight the disadvantages of the methodologies evaluated, which may inform future ethical research, but ultimately it does not provide much insight into ethics.

More broadly, a limitation was the lack of manuscripts that focused on the intersection of technology, ethics, and HIV populations living in rights-constrained settings, making it difficult to identify sufficient research and take-home points based on research. The gap in literature on ethical perspectives and best practices may exacerbate the dangers rights-constrained populations may face in research participation. Overall, one important take-home point from this review is that more research needs to be conducted on these topics to better inform research and policy and improve HIV prevention and treatment efforts.

Conclusion

Ethical perspectives on technology-enabled research may provide insights on the potential risks of harm that key populations may be subject to in research participation. Evaluating concerns from key populations and gathering expert opinion on best practices may help reduce potential risks. Key populations such as those who utilize drug substances and engage in sex work, often live within rights-constrained settings, and face elevated harms to their well-being and freedom due to criminalization. Privacy and confidentiality are of the utmost importance when data leaks may alter the discourse of an individual's life. Participants face potential harms to their physical and emotional welfare due to legal prosecution and stigma. Such harms may compromise their safety and limit their access to healthcare services. Many of these harms may hold long-term consequences and could be potentially deadly due to an increased risk of being targets for stigma-related violence. Through evaluating ethical perspectives and establishing best practices, researchers can work together to limit harm to key populations and create a research environment that benefits and not endangers participants. However, due to the lack of prior research on this topic, additional research is needed to improve HIV prevention and treatment among these underserved and understudied populations.

Data Availability No primary data were collected for this study.

Declarations

Conflict of Interest The authors have no relevant financial or non-financial interests to disclose. The authors have no conflicts of interest to declare that are relevant to the content of this article.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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