

The HIV epidemic in eastern Europe and central Asia: challenges and opportunities

Guest Editors: Miłosz Parczewski, Deniz Gökengin, Andriy Klepikov

Supplement Editors: Alberto Rossi, Loza Biru



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EDITORIAL

The HIV epidemic in eastern Europe and central Asia in difficult times: a story of resilience and change

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The eastern European and central Asian (EECA) region is facing the fastest-growing HIV epidemic in the world with 160,000 (130,000–180,000) people newly acquiring HIV in 2021, an overall 48% increase in the number of new acquisitions, and a 32% rise in AIDS-related deaths over the past 10 years [1]. The World Health Organization East European region is estimated to accommodate 1.4 million people living with HIV (PWH), with the majority of new transmissions reported to occur locally and to be unrelated to cross-country migrations [2, 3]. Sadly, according to UNAIDS, in 2022 only 62% of people living in the EECA region were aware of their HIV status and 51% of PWH received HIV treatment, which resulted in an overall viral suppression rate of 48% [1]. Common (>50%) late diagnoses (with either AIDS-defining condition or CD4⁺ T cell count <350 cells/ μ l at presentation) [4] further add to the epidemiological issues and complexity of client management [5]. Although the key acquisition risk in the region has changed from unsafe injection practices to heterosexual transmission, access to opioid agonist therapy (OAT) and needle and syringe programmes is often still limited (Kazakhstan) or unavailable (Uzbekistan, Turkmenistan), which results in OAT regional coverage as low as 4%, far below the UNAIDS target of 50%.

Furthermore, pre-exposure prophylaxis (PrEP) and combination prevention services are of limited availability or not formally implemented across multiple countries in the region usually due to financial barriers to access, such as lack of state funding for medicines, limited technical capacity or cost of service delivery [6]. This results in a substantially larger HIV PrEP gap (the proportion of populations at risk of acquiring HIV “very likely” to use PrEP if accessible, compared with the proportion currently using PrEP) across countries located in the EECA region (up to 45%) compared to the overall median of 17.4% estimate for the European Union [7]. Moreover, there is a high level of stigma across the countries, especially against gay men and other men who have sex with men.

The growing epidemic and the suboptimal access to prevention, testing and treatment are the main reasons that challenge the 2030 targets.

The humanitarian crisis related to the Russian invasion and war in Ukraine has challenged the situation even further hindering testing and treatment efforts, forcing both internal displacement (estimated 3.7 million) and external migration of locals as refugees (estimated 6.4 million, as of March 2024) [8]. On top of massive casualties, civilian and health-care infrastructures were destroyed, forcing refugees to seek safety, protection and assistance, including continued access to medical care. Ukraine is home to ~260,000 PWH with >130,000 on antiretroviral treatment (ART). Although significant progress was made in the response to the HIV epidemic in Ukraine before the outbreak of war resulting in a 47% reduction in HIV incidence and an 81% reduction in AIDS mortality, the war has significantly affected the HIV and tuberculosis (TB) programmes, with internal displacement resulting in diminished service capacity, difficulty in ART provision and reduction in prevention services [9]. Despite notable hardship, Ukraine managed to maintain full access to ART, increased OAT rollout by 38% (reaching >27,000 people) and doubled the number of people on PrEP, which is now available free of charge [10].

A large proportion of the studies published in this supplement focus on Ukraine and the responses given during the war, providing good examples of resilience and strength and reflecting personal experiences in the setting of mass trauma. Mass traumas are especially important from the perspective of PWH, as these may bring out stress and exacerbate mental health issues. Owczarzak et al. analyse the bioecological model of mass trauma in the context of the Russian invasion and war in Ukraine among PWH with a history of injecting substance use [11]. This study reported the results of 18 interviews with people from four Ukrainian cities in autumn 2022. The study not only outlines personal experiences but also confirms the deep impact of war on the personal and healthcare-related wellbeing of participants, the necessity to respond to the triggering situations, such as the decrease in work opportunities, incremental costs and the necessity for internal displacement. All these factors were shown to be affecting ART access, adherence and general access to healthcare.

Lazarus et al. analysed the non-governmental organization (NGO) response during the war and described service provision for key populations in Ukraine, using a mixed-methods project among geographically dispersed non-governmental ($n = 24$) and governmental ($n = 2$) organizations representing several Ukrainian regions [12]. Their analysis outlines the impact of the war on NGO work, including HIV prevention and treatment in a time when humanitarian aid is critical. Following the initial shock and the terror of war, the majority of the organizations quickly resumed work, limiting the duration of cessation of services, optimizing response and reallocating work to available staff. This study provides a strong story of resilience and support emphasizing the key work of NGOs in healthcare responses during unfortunate “big events” such as war.

The topic of human rights and the context of war in Ukraine is further expanded by Lohman et al. by presenting an assessment related to human rights barriers to the prevention and treatment of HIV and TB [13]. The study consisted of a series of assessments covering the period of the Russian invasion and outbreak of war aiming to examine the progress in the scale-up and outcomes of human rights programmes. The paper describes an implementation learning evaluation using 25 interviews with programme implementers, community advocates and government officials, representing 14 organizations. Interview data clearly reflect the reduction of stigma in several domains, including a decrease in the proportion of PWH who faced unauthorized disclosure in the social environment (−19%), a reduction in the number of reported verbal abuses/personal threats (−13%) and improvement (+33%) in the perceived confidentiality of medical records. The war resulted in the expansion of regional coverage of legal and advocacy programmes and services, allowing a large number of the population to maintain access to key services.

Ukraine is also one of few countries in the EECA region that have implemented numerous combination prevention programmes including HIV PrEP, where adherence remains challenging. In the follow-up of the study on oral daily PrEP with tenofovir disoproxil fumarate (TDF)/emtricitabine (FTC) [14] in 199 people who inject drugs (PWID) in Ukraine with or without the use of text reminders, Morozova et al. analysed longitudinal reported adherence patterns coupled with the measurement of tenofovir diphosphate and emtricitabine triphosphate in dried blood spots from study participants as objective measures of adherence [15]. The study enrolled people who have been injecting drugs for longer than 20 years (37%) with a high proportion of alcohol use (67%) and >50% with moderate to severe depression. In this highly challenging group, the perceived adherence was high to moderate in >90% of the cases with 81% reporting to take more than 95% of their TDF/FTC doses. Alarming, data from the dried blood spot metabolite analysis revealed the reality to be divergent from patient-reported adherence with >50% of participants without detectable TDF/FTC metabolite levels. This study provides unique data confirming the divergence between perceived and measured adherence among PWID, indicating that novel telemedicine or online interventions in combination prevention of HIV can be particularly useful in marginalized or difficult-to-reach populations.

Migrants from central Asia moving to central eastern countries to work are disproportionately affected by HIV and sexually transmitted infections due to high-level stigma and poor working conditions, and have lower or no access to the health system and prevention tools compared to other groups. Kovtun et al. [16] focused on human rights violations related to sexual orientation, gender identity (SOGI), and HIV in six countries in eastern Europe, Caucasus and central Asia in 2022 (Armenia, Kazakhstan, Kyrgyzstan, Tajikistan, Ukraine and Uzbekistan), which have a background of a rapidly rising HIV epidemic, strict social and religious norms, high level of stigma and discrimination associated with sexual and gender minorities and HIV, and regional conflict. Using the Rights—Evidence—ACTion (REAct) tool, they analysed the data on rights violations upon complaints from gay and bisexual men who have sex with men and transgender women. The strikingly higher numbers of rights violations and violations solely based on SOGI in Ukraine compared to the Caucasus and central Asian countries suggest that despite all the achievements made in the country in the last decade in terms of harm reduction, testing, and access to ART and care, stigma and discrimination still prevails in the country. The effect of the recent war in Ukraine was also evident with more human rights violations by police and military staff, denials of private or social services, refusals of temporary accommodation services and denial of border crossings. The results of this study underscore the diversity of the region in terms of stigma, discrimination and human rights violations.

Mackesy-Amiti et al. define a social intervention that aimed to reduce high-risk behaviours for HIV among Tajik migrants who inject drugs working in the Russian Federation [17]. This was a cluster-randomized controlled trial comparing the network-based, peer educator training with the general health education training. Male Tajik migrants were recruited as peer educators and trained on how to reduce personal risk for HIV acquisition and to deliver knowledge to peers. The interviews showed that the baseline percentages of binge drinking, condomless sex, and syringe and equipment sharing behaviours were considerably high, and needle cleaning behaviour and HIV testing were extremely low in both peer educators and peers. There was a significant reduction in needle-sharing behaviour following study intervention, but a modest effect on sexual behaviour. This study suggests that interventions tailored to the needs of specific groups and the inclusion of peers may be effective even in populations that are hard to reach.

Stigma-associated issues were also addressed by Davis et al. who used a citizen science approach to address HIV-related stigma and increase HIV testing in adolescents and young adults in Kazakhstan [18]. These populations were called to develop digital materials, which would be assessed and rated in a contest with the aim to reduce HIV-related stigma and promote HIV self-testing. The submitted materials were judged by a board including peers of the contestants, healthcare professionals and representatives of NGOs, and highly rated submissions were awarded. Adolescents and young adults showed a high level of interest in the project both as contestants, which resulted in a high number of submissions, and as board members providing input in the development and implementation of the study, running social

media procedures, creating promotional materials and providing feedback on the submission system. Inclusion of the community stimulated collaboration among adolescents and young adults, and increased knowledge of HIV-related stigma and the importance of HIV testing.

Lastly, a study also from Kazakhstan on adherence to ART among PWH in association with mental health and cognitive disorders was presented by Mergenova et al. [19]. The size of the HIV epidemic in this country is increasing with the majority of acquisitions reported among people who inject psychoactive substances. The authors performed a cross-sectional questionnaire-based analysis of 230 PWH on stable (>6 months) ART, with the assessment of self-reported ART adherence in addition to depression, anxiety, post-traumatic stress disorder (PTSD) symptoms, and cognitive and memory assessments. Notably, a third of the patients reported a history of mental illness, while only 25% reported injection drug use and 17% hazardous alcohol drinking. Moreover, mild depression or anxiety was reported in 20–32%, while in 6–10%, these mood disorders were at least moderate including PTSD symptoms observed in 7% of cases. Not surprisingly, these symptoms were associated with lower adherence—missing ART was more likely among participants with mild or moderate depressive symptoms, mild or moderate anxiety symptoms, PTSD symptoms or forgetfulness. On the contrary, better cognitive function was associated with better adherence to therapy. This study emphasizes the need for precise and regular assessment of not only ART but also mental health and cognitive function for better care of PWH in order to tailor specific responses and to provide mental health support for improving treatment adherence and maintaining optimal viral suppression rates.

The long history of neglecting HIV in EECA resulted in rapid increases of transmissions. The high number of PWID and migrants who are disproportionately affected by HIV and the unique characteristics of each country with different cultures, beliefs and structures challenge the long-term efforts to address the epidemic. This supplement on the HIV epidemic in eastern Europe and central Asia presents a story of resilience, continued efforts to improve human rights, and innovative approaches to combination prevention, and summarizes key challenges related to stigma and other societal issues. While continuing these efforts, further international support, commitment and collaboration will be vital to achieve the new goals for 2030 to end AIDS in the region.

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COMPETING INTERESTS

The authors declare no competing interests.

AUTHORS' CONTRIBUTIONS

MP and DG jointly drafted and revised the editorial. All the authors read and approved the final version.

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DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no datasets were generated or analysed during the current study.

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RESEARCH ARTICLE

“Will you need this health at all? Will you be alive?": using the bioecological model of mass trauma to understand HIV care experiences during the war in Ukraine

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Abstract

Introduction: Russia's invasion of Ukraine in February 2022 has severely impacted the healthcare system, including the provision of HIV care. The ongoing war is a human-caused mass trauma, a severe ecological and psychosocial disruption that greatly exceeds the coping capacity of the community. The bioecological model of mass trauma builds on Bronfenbrenner's concept of interaction between nested systems to argue that social context determines the impact of life events on the individual and how an individual responds. This paper uses the bioecological model of mass trauma to explore the impact of Russia's aggression against Ukraine and the ongoing war on HIV-positive people who use drugs in Ukraine, a particularly vulnerable population that may be negatively affected by disruptions to social networks, healthcare infrastructure and economic conditions caused by mass trauma.

Methods: Data were collected between September and November 2022. A convenience sample of 18 HIV-positive people who use drugs were recruited from community organizations that work with people living with HIV, drug treatment programmes, and HIV clinics through direct recruitment and participant referral. A total of nine men and nine women were recruited; the age ranged from 33 to 62 years old (mean = 46.44). Participants completed a single interview that explored how the war had affected their daily lives and access to HIV care and other medical services; their relationships with healthcare providers and social workers; and medication access, supply and adherence. Data were analysed using the Framework Method for thematic analysis.

Results: The war had a profound impact on the social, emotional and financial support networks of participants. Changes in social networks, coupled with limited job opportunities and rising prices, intensified financial difficulties for participants. Relocating to different regions of Ukraine, staying at somebody else's home, and losing connections with social workers impacted medication adherence and created lengthy treatment gaps. Participants also experienced a decreased supply of antiretroviral therapy, concerns about accessing medication for opioid use disorder, and overwhelming fears associated with the war, which overshadowed their HIV-related health concerns and negatively impacted medication adherence.

Conclusions: Our analysis reveals the complex impact of war on social networks and healthcare access. Maintaining support networks and competent healthcare providers will be essential amid the ongoing war.

Keywords: HIV; health services accessibility; armed conflicts; Ukraine; substance use; social determinants of health

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1 | INTRODUCTION

Russia's February 2022 invasion of Ukraine took place against a backdrop of an ongoing, 10-year aggression that resulted in the occupation of Crimea and parts of eastern Ukraine. The 2022 invasion has resulted in over 10,000 civilian deaths and around 3.7 million people internally displaced, in addition to 13,000 killed and 1.5 million displaced since 2014 [1–3]. One

year into the full-scale invasion, 66 deliberate attacks on medical facilities have been documented, with 17 of them reporting civilian fatalities [4]. In addition, 1409 healthcare facilities were damaged and 186 have been destroyed [5, 6]. The war has severely impacted the provision of HIV services. A recent report from the Public Health Centre of the Ministry of Health of Ukraine cited that since the onset of the invasion, 38 facilities providing antiretroviral therapy (ART) were shut

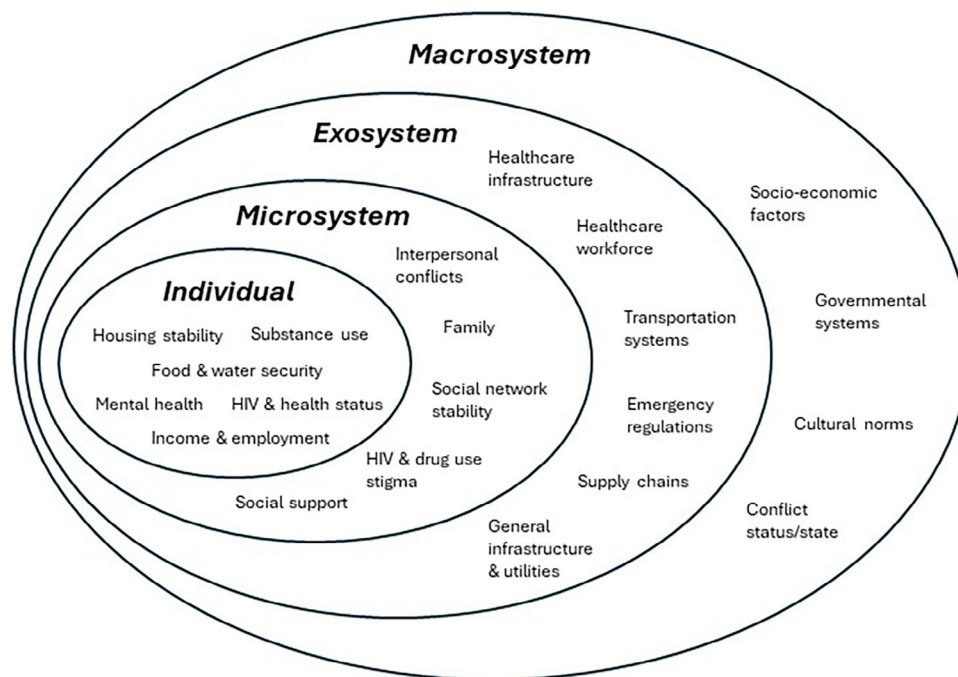


Figure 1. The bioecological model of mass trauma [12].

down, and an estimated 30% of patients on ART have experienced interruptions in medication adherence [7]. In AIDS clinics, reduced staff, overcrowding, and frequent interruptions due to air sirens have limited care providers' ability to track patients and prescribe medications [8]. While supplies of medications for opioid use disorder (MOUD)—an essential approach to increasing HIV care engagement among people who use drugs (PWUD)—were threatened, Ukraine implemented a series of legislative and organizational steps to minimize disruption and support continued MOUD treatment among internally displaced persons [9].

The war can be understood as a human-caused *mass trauma*, a severe ecological and psychosocial disruption that exceeds the coping capacity of the community [10]. Mass traumas (natural disasters, terrorism, chemical accidents, wars) are dynamic events that interact with underlying social determinants of health such as poverty, fragile physical environments and illness to produce human, material, and economic losses and impacts [11]. The *bioecological model of mass trauma* builds on Bronfenbrenner's socio-ecological model, which posits that human development is influenced by interactions within nested systems of influence, ranging from the immediate microsystem to the broader macrosystem, emphasizing the dynamic interplay between individuals and their social and environmental contexts [12]. The bioecological model of mass trauma examines the impact of large-scale traumatic events on individuals and communities, considering the interplay between biological, psychological and environmental factors. It emphasizes the importance of understanding how these factors interact across multiple levels of influence, from individual factors and coping mechanisms to

community resilience and societal responses (see Figure 1) [13, 14]. Mass traumas can exacerbate the challenges that HIV-positive PWUD face [15]. Stress, trauma and uncertainty brought about by mass trauma can exacerbate mental health issues [16–18], further complicating HIV treatment adherence and overall wellbeing of HIV-positive PWUD. Displaced populations or individuals seeking care in unfamiliar places may struggle to identify and access healthcare providers [19, 20]. For PWUD, disruptions in drug supply and availability of injection equipment could destabilize drug use practices, including needle sharing and engagement in high-risk behaviours. Mass trauma can also hinder access to substance use treatment and harm reduction services [21]. Disruption of social support can exacerbate other vulnerabilities, leading to increased risk of HIV outbreaks and major setbacks in the country response to the epidemic [22].

This paper uses the bioecological model of mass trauma to explore the impact of Russia's invasion and ongoing war in Ukraine on HIV-positive PWUD. PWUD are a key population in Ukraine's HIV epidemic, with at least 38% of all people with a new HIV diagnosis and at least 50% of all people living with HIV (PLWH) indicating injection drug use as the route of transmission [23]. In Ukraine, HIV care is delivered through specialized public funded AIDS centres and affiliates; HIV medication and treatment is provided for free to all patients registered with an AIDS centre. MOUD is delivered primarily through governmental sites although about 15% of patients receive MOUD through private clinics [9]. Understanding how the war affects this population and the strategies they use in response can inform efforts to improve post-trauma healthcare and help them remain engaged in care.

2 | METHODS

Data for this paper were collected as part of formative research for a larger study on HIV care retention among Ukrainian HIV-positive PWUD being conducted in four cities (Kyiv, Odesa, Poltava and Dnipro). Data were collected between September and November 2022. A convenience sample of participants was recruited from organizations that work with PLWH, drug treatment programmes and HIV clinics. Inclusion criteria were: (1) being at least 18 years old; (2) living in one of the study cities; (3) confirmed HIV diagnosis; (4) history of injection drug use; and (5) able to consent and willing to participate. A research team member contacted potential participants, provided them with more information about the study and completed eligibility screening. All participants provided oral informed consent. Study procedures were reviewed and approved by the Institutional Review Boards at Johns Hopkins Bloomberg School of Public Health and the Ukrainian Institute on Public Health Policy.

Participants completed a single in-person interview that explored social status and support (e.g. housing, financial situation and family relationships); substance use experiences; HIV treatment and care; relationship with healthcare providers; and access to other medical services, including drug treatment. Participants were asked about how the war affected their daily lives, access to healthcare, relationships with healthcare providers and social workers, and ART and MOUD access, supply and adherence. Interviews were conducted in either Russian or Ukrainian, based on the participant's preference. Interviews lasted around an hour and participants received the equivalent of \$15 (400 UAH) as compensation.

All interviews were transcribed, translated from Russian or Ukrainian to English, and uploaded to MaxQDA 2022 for analysis [24]. Analysis began by summarizing each participant's personal background, HIV diagnosis and care history, and drug use and treatment history. Then, experiences around the war were coded and summarized using a modified framework method [25]. Codes were developed both deductively and inductively by exploring *a priori* topics that aligned with the bioecological model of mass trauma but remained open to emergent concepts. Codes included the impact of war on HIV services, family/social network, financial situation and psychological wellbeing. Codes were also developed around access to medical services, medication adherence and relationship with healthcare providers, including communication. Two coders independently coded all transcripts with the coding system, periodically checking for consistent use of codes. After each participant's transcript was coded, a summary profile was written for each participant for each code. These summaries were then analysed across participants to identify the range of experiences around receiving HIV care during the war.

3 | RESULTS

Eighteen participants across all study cities completed in-depth interviews (Dnipro: $n = 4$; Kyiv: $n = 5$; Odesa: $n = 5$; Poltava: $n = 4$). Participants were split evenly by sex ($n =$

9 female, $n = 9$ male); the age ranged from 33 to 62 years (mean = 46.44). Almost all participants were living with family and/or partners at the time of the interview; half of them were married, others were single ($n = 6$) or widowed ($n = 3$). Less than half ($n = 7$) were employed full-time or part-time, and 11 were unemployed, working occasional jobs and/or on disability status. Almost all participants had secondary education or technical training. Most had been diagnosed with HIV over 5–10 years before the interview (range: 3–30).

3.1 | Social support and socio-economic precarity

The start of the war prompted evacuations away from the frontlines and cities that were directly targeted by Russian ground and aerial attacks and tens of thousands of people have been drafted into the military. These movements brought significant changes to participants' social networks with implications for social, emotional and financial support. Participants described how some friends and family who used to provide support—running errands, household chores, or financial aid—had moved and were no longer able to help. Dnipro P01, a 47-year-old single mother, had difficulty maintaining contact with her oldest son, who joined the army. When asked if there were people she could turn to for support, she described how her close friends had moved, although she tried to stay in touch with them by phone:

She was my social worker... I still keep in touch with her. Then I have a friend who is in Norway now, but I communicate with her too. There are a few more girlfriends. There is a neighbor who lives in Poland now. We used to be in close contact with her. But now, unfortunately, there is no such opportunity, but nevertheless we communicate with her. (Dnipro P01, female, 47 years)

Some participants also talked about the people who relied on them. These mutual obligations shaped their decisions around whether to move farther from the front lines or to stay close to care for older relatives or in areas where they had strong social ties. Odesa P04, a 51-year-old man, did not consider moving when the full-scale invasion started, citing a close relationship with his elderly mother, who stayed in Odesa. They communicated often and supported each other as much as possible. When asked to elaborate on what led him to stay in Odesa, he said:

First of all, I've lived here all the time, I was born here, I have a circle of friends here, and my mother also lives here. Plus, my medicines, all my doctors - everything is here, I'm tied to this place even through getting my medicines. (Odesa P04, male, 51 years)

Participants' narratives also highlighted the complex and dynamic relationships between social/familial networks and their financial situations. Familial support was crucial in buffering against the challenging financial circumstances introduced by the war. Participants noted the dual strain of increased costs of household goods and lost employment or reduced work hours for both them and their partners. For

Kyiv P04, a 38-year-old woman, her husband's inability to find work made it difficult for them to support each other, particularly because they had young children, and strained their relationship. Odesa P05 and his wife received disability pensions; they made ends meet but were uncomfortable. He occasionally found work as a construction contractor, but these jobs were scarce, particularly since the onset of the war. Making sure that he and his wife could support their children was a significant stressor—for example they often made personal sacrifices to ensure that their children's needs were met:

My children have shoes, clothes, food. Money is indeed running out very quickly. [...] I'm already behind the shopping schedule, because I bought everything for my family, but myself, I still wear my summer shoes and my autumn jacket, roughly speaking. The main thing is to have enough money for the kids. As for myself, I'm used to it. We manage somehow. (Odesa P05, male, 43 years)

Dnipro P03, a 42-year-old man, summarized the problem succinctly: "[There is] not enough money. Especially lately, because of the war. You know, the prices have risen and there is less work. In general, money is a problem now. I'm not starving, but I'd like to have more money." Many participants relied on cobbling together income and resources from multiple sources, such as disability pensions, humanitarian aid and food rations to make ends meet.

Although most participants could meet basic needs and secure housing independently or with family support, one participant, Odesa P03, a 31-year-old man, was often unhoused and could only check into hostels when he had money. He was not sure about any potential solutions because it had become increasingly difficult to find jobs in the informal labor market:

To be honest, I don't know anymore, I don't even know - either to turn to God or to whom... Before the war, workers were gathered here in parks, paid 200, 300 hryvnias a day, and we went to construction sites, worked, and earned 250-300-350 hryvnias [7-9 USD] a day; somehow it was easier. Now, with the outbreak of the war, there is no such work. And if there is work somewhere, then everything must be official - all documents, you need an employment history, and so on. And I don't have it. (Odesa P03, male, 31 years)

3.2 | Healthcare networks and care engagement

The war affected access to HIV services and other medical care in several ways, including changes to the individual and network of providers who helped people access and remain in care. In Ukraine, social workers play an important role in helping PLWH stay connected to care. Participants often had friendly, sustained relationships with social workers, whose phone calls and text messages helped them solve issues they encountered accessing care. As with other healthcare workers, some social workers left Ukraine at the start of the war and did not return. The loss of a social worker could have both temporary and longer-term effects on people's ability to access care. Participants worried about the sometimes long

and difficult process of finding and getting to know a new provider. At the start of the war, Kyiv P02, a 46-year-old woman diagnosed with HIV in 2015, became disconnected from her social worker and MOUD provider who left the region at the start of the war. She had to use her own contacts to find a new social worker.

Many participants experienced treatment gaps at the onset of the war, ranging from a few days to several months. Social workers played an important role in helping participants access medication and remain adherent throughout the war, for those who remained on treatment and for those who experienced treatment gaps. After a 1.5-month treatment gap, Dnipro P01 connected with her social worker over text message, and her social worker motivated her to resume taking her medications:

I communicated with her by text messages, and she just did not suspect it right away. And only later, when I wrote to her, I said: "I quit the medications." And she said: "I don't even want to hear anything. Resume taking medications again." And somehow, I have had such a relationship with her for so many years, that's why she is already like a sister to me. She tells me: "When I come, I'll give you a hard time." And that's all, I listened to her and started taking [medications] again. That's how it is. (Dnipro P01, female, 47 years)

Importantly, the sustained and trusting relationship with her social worker motivated the participant to return to treatment. Participants who did not experience treatment gaps also attested to the positive impact that their social workers had on their adherence during the war. At multiple time points, participants received the option from their social workers to either continue picking up medications in person at the AIDS centre or opt into the free delivery service. Participants also attested to consistent and frequent check-ins and ongoing support with adherence throughout the war.

Participants who left their home cities at the beginning of the invasion encountered changes in their immediate social networks and surroundings that had implications for access to care and medication adherence. Several participants took up residence with relatives and acquaintances who were unaware of their HIV status, leading to concerns about disclosure. Kyiv P05, a 51-year-old-male who relocated to Kolomyia (in western Ukraine) with his wife to live with acquaintances, worried about seeking out HIV care due to concerns for his privacy:

We live with my acquaintances; they don't know I have HIV status and I don't want them to know. They will notice if I'm looking for some kind of facility. I don't want everyone to know about it. (Kyiv P05, male, 51 years)

His concern about revealing his HIV status resulted in a months-long treatment gap, with plans to re-initiate treatment upon his return to Kyiv.

Temporary relocations could result in changes to familiar forms of support that undermined adherence. Kyiv P02, a 46-year-old woman, temporarily relocated to western Ukraine to live with her parents' friends. She was away from her parents

during this time, on whom she relied for support and reminders to take her medication. Before the war started, her father would ask about her HIV and associated treatment: Sometimes my father asks me: “How are you? How are the analyses? How do you take your drugs—do you skip it or not?” While she was in western Ukraine, she also lost contact with her social worker, who had left Ukraine and could no longer be reached. Through one of her contacts, she found and organized a consultation with a new social worker. He informed her that she could receive treatment in western Ukraine and offered to send her medication through the free delivery service. She declined and decided she would re-initiate treatment when she returned to Kyiv, which she did after 2–3 months of missing treatment.

Participants’ healthcare networks could also be disrupted through the influx of new patients due to internal migration in some regions. As a result, wait times increased in many primary care clinics, creating barriers for patients’ registration with a primary care provider before seeing specialists. For example, Kyiv P02 wanted to see a gynaecologist but could not get a referral from a family doctor in Kyiv, who was not accepting any new patients. Additionally, two participants from Poltava described how the HIV hospital was closed and repurposed for military medical care. This did not impact their access to routine HIV care, which they received from a different centre, but they were concerned that if they needed in-patient treatment or other general medical care, it may be difficult for them to access in non-specialty hospitals based on prior experiences with discrimination based on HIV status.

3.3 | Infrastructure and uncertainty

Changes and damage to physical infrastructure and supply chains created both actual and anticipated treatment gaps. At the start of the full-scale war, halts in public transportation meant that people could not attend clinic appointments. Temporary interruptions in public transportation impacted participants who relied on picking up their medications in person. For Kyiv P01, a 37-year-old woman, these interruptions prevented her from accessing the AIDS centre and retrieving her medications at the onset of the war, ultimately leading to a 4-month treatment gap. Another participant, Odesa P01, a 50-year-old woman, was unable to go to the clinic to get her medication when public transportation was stopped. However, in her case, she was able to get in contact with her social worker, who delivered medications to her and thus prevented a treatment gap:

It was impossible to go [to the clinic] in the first month of the war; it was impossible. On the 24th of February, the war began, and on the 27th, I ran out of drugs. And the [social workers] called me, they said: “Can you come to us?” I say: “How?” I almost cried. And they immediately rushed in and brought both humanitarian aid and pills to me. (Odesa P01, female, 50 years)

When public transit resumed, access challenges persisted. Participants from Kyiv mentioned air raid alarms resulting in sudden clinic closures. During anticipated air raids,

social workers advised patients to stop clinic visits and opt for receiving mail-delivered medication and rescheduling lab appointments. A 38-year-old woman from Kyiv, who had been living with HIV for 5 years and preferred to attend the clinic in-person, described the impact of the frequent air raid alarms:

When the air [raid] alarm sounds, we’re out, right? They kick you out of the room: “Wait outside for the alarm to go off, then come back.” And there are 50 people near the AIDS Center waiting. This air alarm can last for 3, 4, and 5 hours. But we still need to receive therapy or take tests. [...] We cannot wait 2–3 hours every time. (Kyiv P04, female, 38 years)

In addition, before the full-scale invasion started, most participants described an established schedule and routine for acquiring their medications, typically receiving a 3-month supply of ART each time. Most participants picked up their medications in person at their local AIDS centre, while others opted for a free mail delivery service, which was operationalized during the COVID-19 pandemic. At the onset of the war, many participants noted a decrease in supply (from 3 to 1 month), which eventually stabilized.

Participants who were on MOUD worried about continued access at the onset of the war. Dnipro P02, a 45-year-old man diagnosed with HIV in 2001, who had been on methadone maintenance therapy for 10 years, stated that he was very worried about potential gaps in MOUD when the conflict started. After hearing stories of methadone factories being bombed, he actively looked for other programmes in surrounding cities and even abroad. Luckily, he did not have any issues with access throughout wartime. Though he has had treatment gaps in ART in the past, he seemed to be more concerned about the consequences of not having access to MOUD:

You know, to be honest, if I had to choose between ART and OST [opioid substitution therapy], I would probably choose OST so that I have access to the OST, and ART is in second place. No ART, of course, also worries me. I can’t say that I don’t give a damn if I have it or not. But, first of all, I need OST. (Dnipro P02, male, 45 years)

For some, concerns about continued access to MOUD stemmed from stories of the 2014 Russian occupation of Crimea and its impact on drug treatment programmes. Odesa P04, a 51-year-old man living with HIV since 1997, said that he had been working with his doctor to gradually reduce his dose of methadone in case there are interruptions to MOUD programmes. He recalled the experience in Crimea:

I watched on TV, in 2014, when they occupied Crimea, there was a [MOUD] program there too. They showed on TV how they asked Putin not to interrupt their program. [...] They say many people have died; many have left Crimea. Here in Odesa, we had a few people who recovered here and started taking medication. (Odesa P04, male, 51 years)

Kyiv P02 moved from Kyiv to Lviv (in western Ukraine) at the onset of the war. She had similar worries about MOUD access but was able to transfer from a Kyiv-based programme to a Lviv-based programme after learning how to through social media. As a result, she had no MOUD treatment gaps. However, she did not transfer to a new HIV care facility to continue ART and instead waited until her return to Kyiv to resume treatment. She also expressed greater concern for missing a methadone dose compared to an ART dose, because she would feel a missing methadone dose immediately.

Fear about the war also impacted medication adherence. Participants often described feeling overwhelmed and distracted, particularly at the onset of the full-scale invasion. Having a supply of ART did not always guarantee that participants continued to adhere to medication regimens. Kyiv P02 explained that worry and stress around the war displaced her worries about her own HIV-related health:

Because there was a fear of war, I guess it was somehow bigger than those [HIV-related] fears, I didn't feel that fear... At first, the war came to the fore, and only later – my health. Because you did not understand – will you need this health at all? Will you be alive or not? (Kyiv P02, female, 46 years)

4 | DISCUSSION

Our analysis illustrates the intersectional and multifaceted traumas and stressors that resulted from war, whose cascading effects disrupted participants' social networks and healthcare access for PLWH, especially those who use drugs. Although participants were mostly able to make ends meet after the start of the invasion, their social networks were under considerable strain. They had to draw on multiple social network resources to cobble together a living. Participants and their healthcare providers described pragmatic innovations to sustain access to healthcare and essential medications. These innovations, such as mail-delivered medications and extended medication supplies to decrease the need for clinic visits, were tremendously beneficial to participants and allowed them to either stay engaged or quickly reconnect with care providers after a brief disruption. Not all participants knew how to contact providers during the early phases of the full-scale invasion and others were not aware of the changes to medication prescribing and delivery practices. However, social media and other online forums provided crucial information channels for participants to quickly learn about changes. Supporting both providers and clients to use these forms of communication can be important tools to keep people engaged in care. While the interviews primarily focused on access to HIV care and substance use treatment, some participants noted that they were unable to access other types of necessary care, such as general primary care.

The bioecological model of mass trauma suggests that it is necessary to look beyond individual-level effects and responses and consider the interconnections between individuals, systems and communities to understand the immediate and long-term effects of large-scale disasters and catastrophes [14]. For HIV-positive PWUD, specific attention must be

paid to the unique factors that affect their ability to access and remain in care, including MOUD [26]. Participants in this study described how they mitigated negative outcomes following exposure to traumatic events, including drawing on their social networks for support. However, research among PWUD has demonstrated that this population may have less access to sources of financial and other forms of support due to stigma, strained family relationships and reduced opportunities for employment [27–29]. For PLWH, a lack of supportive networks can also undermine HIV care engagement [30, 31]. As the war continues, the extent to which social networks can remain a source of financial and other forms of support is unknown. Moreover, HIV-positive PWUD continue to face stigmatizing attitudes and behaviours in healthcare settings [32] and require experienced, empathetic and accessible providers to remain in care. In the context of strain on the healthcare workforce, exacerbated by lingering effects of the COVID-19 pandemic, how HIV-positive PWUD find and maintain relationships with competent providers will be an important component of understanding the long-term effects of the war.

Ongoing war threatens further disruptions that can undermine resiliency at multiple levels. For example, conflict in the Tigray region of Ethiopia resulted in a significant loss to follow-up of patients with chronic disease, including HIV [33]. Their experiences highlight the importance of proactive efforts to engage people in care during periods of stability and strategies that foster resiliency at the individual, network and community levels [34]. At the individual level, psychosocial support can be built through individual counselling and support groups that focus on developing adaptive coping mechanisms (e.g. seeking social support, problem-solving) and skill-building [35, 36]. Such efforts must be grounded in best practices of a trauma-informed approach, which prioritize physical and emotional safety, trustworthiness, peer support, individual autonomy, flexibility and a focus on strengths [37]. Healthcare facilities and healthcare leaders can draw on the insights gained over the 2 years of the full-scale invasion, during which they adapted by redefining their service offerings, providing additional training to first responders, deploying mobile modular services to reach patients despite the obstacles presented by damaged roads and enlisting the assistance of the national community of disease specialists to bolster care delivery for vulnerable populations [38].

The war and its consequences do not occur in a vacuum and the trauma participants currently experience did not begin in February 2022. Rather, it takes place in a context informed by both the COVID-19 pandemic and Russia's 2014 invasion of Ukraine. As others have noted, COVID-19 ushered in positive changes to healthcare and medication delivery that benefited PLWH and people on MOUD at the start of the full-scale war. In Ukraine, interim Ministry of Health guidance allowed less stringent criteria for existing MOUD patients (of whom 40–45% have HIV [39]) to transition to take-home dosing (mostly 10-day supplies) [40]. As a result, procedures were in place at the start of the war that allowed to extend the maximum supply up to 30 days, therefore, decreasing the need to travel to clinics [9]. At the same time, COVID-19, in Ukraine and globally, created considerable strain on the healthcare workforce, including

increased workload, staff shortages, mental health challenges, and quickly changing work dynamics and workflows, leading to burnout and exodus from the profession [41]. The people we interviewed experienced the consequences of these strains directly, for example with social workers and infectious disease physicians having left the country.

In addition, following the Russian invasion in 2014 and subsequent annexation of Crimea, PLWH and PWUD witnessed first-hand what the consequences of a Russian takeover of Ukrainian territory could mean for their health and wellbeing. In Ukraine, considerable investment has been made to increase the availability and access to MOUD [42]. However, MOUD is banned in Russia, and after the annexation of Crimea in 2014, hundreds of MOUD patients immediately lost access to this medication resulting in over 100 deaths from fatal opioid overdose, suicide and other causes [43, 44]. Other MOUD patients fled Crimea for mainland Ukraine to maintain access to this life-saving medication. Our participants feared similar outcomes if Russia claimed new territories in the current war.

This paper has several limitations. First, data were collected as part of formative work to inform intervention design. Although war was discussed in the interviews, it was not the focus of the interview. We anticipate that interviews focused solely on the war would yield richer insights into issues related to social networks and mental health, for example. While study participants tended to emphasize positive developments and proactive responses to keep people in care, research from other conflict-affected regions has found that war can significantly decrease healthcare utilization even in areas that are not sites of active conflict [45]. In addition, the study sample was limited to individuals who stayed in Ukraine rather than those who moved abroad. The latter likely faced unique challenges, such as navigating unfamiliar bureaucracies, learning a new language and finding ways to pay for care [46–48]. Finally, although we tried to interview people who were out of care, we were unable to recruit participants who had little contact with the healthcare sector. As a result, the experiences of our participants in many ways may represent “best case scenarios” and not the full impact of the war on HIV care engagement, particularly among the most marginalized and disengaged.

5 | CONCLUSIONS

The ongoing war following the full-scale Russian invasion of Ukraine has severely damaged medical infrastructure and HIV care. Participants experienced significant disruptions in their physical environments, economic stability and social support systems, which impacted their access and adherence to ART and the provision of HIV services. This was compounded by psychological stress, fear, and feelings of uncertainty. Most participants we interviewed demonstrated resiliency and creativity in response to Russia's invasion of Ukraine. In contexts of mass trauma and disruption, in addition to aid to meet basic needs, strategies should be devised to create forms of social support that help people to remain engaged in care, particularly considering the potential shortages in financial and other material resources.

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COMPETING INTERESTS

The authors declare that they have no competing interests.

AUTHORS' CONTRIBUTIONS

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RESEARCH ARTICLE

“...because the social work never ends”: a qualitative study exploring how NGOs responded to emerging needs while upholding responsibility to HIV prevention and treatment during the war in Ukraine

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Abstract

Introduction: Since the onset of the Russian invasion on 24 February 2022, the health system in Ukraine has been placed under tremendous pressure, with damage to critical infrastructure, large losses of human resources, restricted mobility and significant supply chain interruptions. Based on a longstanding partnership between the Ukrainian Institute for Social Research after Oleksandr Yaremenko (UISR after O. Yaremenko) and the Institute for Global Public Health at the University of Manitoba, we explore the impact of the full-scale war on non-governmental organizations (NGOs, including charitable organizations) providing services for key population groups in Ukraine.

Methods: We conducted in-depth qualitative interviews with key representatives from NGOs working with key population groups (i.e., people living with HIV, sex workers, men who have sex with men, people who inject drugs and transgender people) throughout Ukraine. Members of the UISR after O. Yaremenko research team recruited participants from organizations working at national, regional and local levels. The research team members conducted 26 interviews (22 with women and four with men) between 15 May and 7 June 2023. Interviews were conducted virtually in Ukrainian and interpretively analysed to draw out key themes.

Results: Applying Roels et al.'s notion of “first responders”, our findings explore how the full-scale war personally and organizationally impacted workers at Ukrainian NGOs. Despite the impacts to participants' physical and mental health, frontline workers continued to support HIV prevention and treatment while also responding to the need for humanitarian aid among their clients and the wider community. Furthermore, despite inadequate pay and compensation for their work, frontline workers assumed additional responsibilities, thereby exceeding their normal workload during the extraordinary conditions of war.

Conclusions: NGOs play a vital role as responders, adapting their services to meet the emergent needs of communities during structural shocks, such as war. There is an urgent need to support NGOs with adequate resources for key population service delivery and to increase support for their important role in humanitarian aid.

Keywords: HIV; NGO; key populations; conflict; war; Ukraine

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1 | INTRODUCTION

Russia's invasion of Ukraine on 24 February 2022, has led to ongoing disruptions to health and social services across the country [1–3]. In Ukraine, HIV treatment is funded by the state, and its provision is centralized through AIDS Centers within each region [4]. At the same time, HIV prevention services are almost exclusively funded through international donors, such as the Global Fund and the United States Pres-

ident's Emergency Plan for AIDS Relief (PEPFAR), and delivered through non-governmental organizations (NGOs) [5–8]. NGOs provide HIV prevention services and resources to key populations (sex workers, men who have sex with men, people who inject drugs and transgender people), including harm reduction supplies, condoms and counselling and testing for HIV and other sexually transmitted and blood-borne infections [6, 9]. During the Donbas war (2014–2022), Ukraine began a multi-year, multi-pronged healthcare reform process [10, 11],

transitioning funding for HIV care and treatment from international donors to the government in 2021 [4, 12]. However, with the war came another influx of international donor support, with some funding earmarked for HIV treatment and prevention [12]. In 2022, the Global Fund and PEPFAR provided 85% of the HIV budget, and in 2023, the Ukrainian government provided no funding for HIV. In the first year of the war, foreign donors provided in excess of 38 million USD in emergency funding for HIV prevention and treatment services [13–15].

The Ukrainian healthcare system has been under immense pressure since the war, with damage to critical infrastructure, large losses of human resources, restricted mobility and significant supply chain interruptions [12, 16–19]. As of 5 January 2024, the World Health Organization registered 1435 attacks on healthcare facilities, including 218 injuries and 112 deaths of both patients and personnel [3]. Approximately 38 out of 392 antiretroviral therapy (ART) sites have shut down, and laboratories in the occupied Donetsk and Luhansk oblasts have discontinued their operations [17, 20]. The displacement of medical staff and social workers has strained the human resources available for providing HIV treatment and prevention [16, 17].

At the end of 2021, an estimated 245,000 people were living with HIV (people living with HIV [PLHIV]) in Ukraine, 152,000 of whom were on ART [21]. As of December 2023, the registered number of PLHIV in Ukraine was 158,803, and according to the Public Health Center of the Ministry of Health of Ukraine data, as of November 2023, there were 121,820 people receiving ART [22]. While current HIV incidence and prevalence data are not available, reports from 2021 indicated an HIV prevalence of 0.94% among adults 15 to 49 [21]. In the same year, the HIV prevalence was 3.1% among sex workers and 3.9% among men who have sex with men. Data from 2020 showed an HIV prevalence of 20.3% among people who use injection drugs and 1.7% among transgender people [21]. The supply of enough ART during the war has been assured by partners including the Global Fund, the Joint United Nations Programme on HIV/AIDS (UNAIDS), the United States Agency for International Development (USAID) and PEPFAR [13, 23, 24]. Despite adequate supplies, approximately 30% of PLHIV reported disruptions to treatment since the onset of the war [17]. Historically, there have been higher rates of HIV in eastern Ukraine [25], which currently includes Russian-occupied zones [26] and has resulted in missing data on whether PLHIV are receiving the care that they require [20]. Even amidst the full-scale war, access to ART was ensured for all who required treatment within government-controlled territories [27].

NGOs play an important role in providing HIV prevention, treatment and care in Ukraine, especially for key populations [9, 28]. NGOs that focus on providing services to people who use injection drugs have significantly expanded access to HIV prevention, care and treatment, connecting key populations to essential HIV-related services [29–31]. Notably, in 2022, NGOs managed to achieve substantial coverage of prevention services. Despite the war, 62% of registered NGO clients received prevention services, and approximately 84% were tested for HIV [32]. In 2023, collaboration between 88 NGOs providing HIV services and the Public Health Center worked

to further strengthen care and support efforts for PLHIV and prevention services for key populations. These NGOs are strategically distributed across various regions, with concentrations in Kyiv, Dnipro and Odesa oblasts. Among the 88 NGOs, 58 focus on HIV prevention programmes for people who inject drugs, 33 for sex workers and 33 for men who have sex with men. Additionally, 10 organizations provide prevention services for transgender people, and six provide services to incarcerated populations, with multiple organizations often serving more than one key population [32].

Drawing on a longstanding partnership between the Ukrainian Institute for Social Research after Oleksandr Yaremenko (UISR after O. Yaremenko) and the Institute for Global Public Health at the University of Manitoba, we aimed to explore the impact of the war on NGOs providing HIV prevention and treatment services for key population groups across the country.

2 | METHODS

This study builds on the work of the *Dynamics Study*, a mixed-methods project exploring the impact of conflict on sex work and the HIV/hepatitis C (HCV) epidemics in Dnipro, Ukraine [33]. After the COVID-19 pandemic and the onset of full-scale war, our team refocused study activities towards conducting a series of in-depth, key informant interviews with representatives from NGOs working with key population groups across Ukraine. Interviews explored how participants' programmes were impacted and adapted during the war. The UISR after O. Yaremenko research team enrolled participants from NGOs working at national, regional and local levels. Participants were aged 18 years and older, had at least 2 years' experience providing services to key population groups and had experience providing services during the war in Ukraine (i.e., since February 2022). More broadly, organizations were selected to ensure representation of (i) regions across the country, (ii) service provisions for different key population groups, (iii) level of operation (national, regional and local) and (iv) types of services (social-medical and social).

A trained team of interviewers conducted 26 interviews with individuals representing 24 organizations between 15 May and 7 June 2023. Twenty-two of the participants were women and four were men and included: five interviews with organizations that work nationally; three interviews with organizations that work in central Ukraine; three interviews with organizations that work in the West; eight interviews with organizations in the East, including cities that were under Russian occupation and have experienced both wars (2014 and 2022); two interviews with organizations that work in the North; and five interviews with organizations in the South, including cities that were under Russian occupation after February 2022. Twenty-four of the participants represented NGOs (including charitable organizations), and two were from governmental organizations. In discussion with local partners, we only identify participants by the region in which they work to protect their confidentiality and anonymity during an ongoing war across the country. Questions explored how participants were impacted by the war; how their organizations were impacted and how their work might have changed;

how service provision was affected, especially as it related to services for key populations; and how these changes have impacted their clients. Interviews were conducted virtually in Ukrainian, recorded and transcribed, and then translated into English.

All participants provided verbal, informed consent to participate in the study, and ethical approvals were obtained from the Health Research Ethics Board at the University of Manitoba, Canada, and the Ethical Review Committee of the Sociological Association of Ukraine.

2.1 | Analysis

We borrow the concept of “first responders” from Roels et al.’s study on the responses of community-based organizations working with youth in Amsterdam and New York City during the COVID-19 pandemic [34]. As Roels and colleagues note: “...mechanisms of well-being are foundationally relational. They depend upon ‘connectivity’, the dense connections that develop between partner organizations and the communities and participants they serve” [p.2].

We draw on the notion of first responders to evoke how Ukrainian NGOs are often first to respond to what Friedman et al. have called “Big Events” [35–37]—moments of war, pandemics and political change—due to their “connectivity” to communities and their “nimbleness” to quickly respond and adapt their services as needed [34]. The concept of first responders informed our thematic analysis exploring the impact of the war on NGOs serving key populations across Ukraine.

The first two authors (LL and LMM) independently reviewed and inductively coded the first six transcripts to develop a simplified coding scheme aimed at sharing findings back with participant organizations and government partners to help inform their work. The first author (LL) then thematically coded the remaining transcripts using NVivo 12 software, drawing on an interpretivist lens [38]. Preliminary findings were shared and discussed with the research team before finalizing analyses.

3 | RESULTS

In the sections below, we present our findings on the following themes: (1) how participants and their work were impacted by the escalation of war; (2) how frontline workers continued to support HIV prevention and treatment while also responding to the need for humanitarian aid among the wider community; and (3) how frontline workers went above expected responsibilities, despite inadequate pay and compensation for their work.

3.1 | Continuing to provide services under the extraordinary conditions of war

Participants spoke of the initial shock of the launch of full-scale war on 24 February 2022. Despite initial feelings of terror, many participants soon resumed their work responsibilities.

Well, probably like everyone else, I was in shock. There was such a panic at first. Because we really didn't know what was going to happen tomorrow. We didn't know what would happen tomorrow, not only to our organization, to our work, to our clients.... Because those first air sirens were very traumatic.... For the first period, I don't know what period, I don't remember now, we didn't go to work. But a person adapts to everything. You start to get used to everything. You realize that you need to move on. Slowly, slowly, we began to recover and resume our activities and services. Because our clients still have needs.... (Microregion: West)

Disruptions to services appeared to last for incredibly short durations, as staff returned to work to respond to their clients' needs, and responsibilities were reallocated among staff who stayed. Despite the impact to their own realities, participants spoke of their responsibility to return to work as a primary source of support to their clients, who reached out to them for information, as illustrated in the quotation below:

... but despite the fact that we did not know whether we would be paid for our services, we still went to work, because already a large number of people started calling from the very first day in complete confusion as to how everything will happen next. How will it be possible to take medicine in the future? Where will it be possible to take it? Will AIDS Centers and trust offices work? Will it be possible to take these medicines for free? For what period of time? For what period? How will the treatment of HIV-positive people take place, or ART drugs will be purchased? ... I tried to assure the people who contacted me that everything will be fine, that nothing will be interrupted, that the treatment will continue as it was.... (East)

NGO workers returned to work, at their own risk and amidst grave uncertainties, to adapt services to the current reality of war while facing staffing shortages, shelling, bombings and at times, destroyed workplaces. Some organizations operating in cities that were attacked and occupied moved their services to be based out of non-occupied cities nearby.

Well, what changed? Life changed very much, for the worse. Because many people left. Those specialists who had worked in the organization for many years and whom we had trained, they left, and the organization became bare. We have to train new specialists now. When we worked during the occupation, it was a daily risk. Now it's a daily risk of being hit by shelling and being killed. It's a daily risk, minute by minute, hour by hour. (South)

NGOs and their staff assumed these personal risks to continue providing their clients with necessary treatments—ranging from ART to opioid substitution therapy (OST) and hormone replacement therapy (HRT)—despite the increased risk of providing services to criminalized populations, including men who have sex with men, people who use drugs and transgender people, under Russian occupation.

3.2 | Continuing to prioritize HIV prevention and treatment while also responding to humanitarian needs

At the onset of war, NGOs and frontline workers turned their attention towards mobilizing resources to provide humanitarian aid to their clients.

As an organization [name], we did not stop our services for a single day. We worked on February 24.... We added new services immediately to our clients. We communicated very quickly with some donors and donors communicated with us. On February 28, we started paying out financial aid to our clients. To those whom we could, directly to the cards. This is something that [organization name] has never done before, because we did not have such a need. Not even such a need, not even such an opportunity.... (National)

NGOs adapted to meet the basic needs of their clients, tapping in to both their donor and client networks, to provide essential goods such as hygiene products, power banks, clothes, food kits, certificates for groceries and financial aid. Services were expanded beyond key population groups to reach internally displaced people and also included requests for psychological support and replacing lost documents, which are especially necessary for accessing healthcare and medications.

Well, in the first place, it is humanitarian aid, which remains the most common need: food, medicine, especially medicine, hygiene products, means of prevention. In winter, for example, when they started bombing power plants, there was no light, no heat, so we were bombarded with requests: we needed warm blankets, flashlights, power banks. That is, what we all needed here, so did they. And we bought it all, if possible, there: sleeping bags, tents, thermal underwear. Well, we had a very long list of things they needed. Now, of course, it is already warm, and all this has faded into the background. Now more products, medicines, hygiene products and plus, again, housing remain relevant, because most people live in rented apartments.... (National)

While individual priorities shifted towards basic needs and survival during war, NGOs continued to stress the importance of HIV prevention and treatment to their clients. Participants stated that their clients shifted their attention to immediate concerns; however, in their roles as frontline workers, they continued to stress the need for testing and treatment—pointing to the importance of protecting the long-term health of their clients beyond the immediacy of war.

.... The war has changed the values in each of us, the attitude to life, it is the priority of what life should be given to. And people who had a well-established life, work, life, they had everything, then they could concentrate some attention on their health. Now it is not a priority, now it is a priority to survive, to eat, and people's heads are full of other things. And people now refuse,

'nothing hurts me' and they turn to in extreme cases, when they have acute pains or something. And they don't want to think about HIV, which doesn't bother them at all. Therefore, our specialists and social workers spend more time now motivating people, building commitment to what needs to be done. Because no one has cancelled the epidemics. More time is spent on these explanations. We have more people who refuse our services. This, of course, has a very strong psychological effect on our employees and makes it difficult to work. But it is ok, now it is difficult for everyone in the conditions of war. (East)

Participants spoke of the additional work and stress that went into encouraging clients to continue prioritizing ART to maintain their health. They also described their expanded roles serving as sources of information on accessing treatment for newly displaced people and clients who had relocated, both within and outside of Ukraine. Participants at times kept in touch with these clients and provided information on other organizations they could access for treatment and support. Frontline workers also maintained access to ART through outreach, shifting to mobile clinics, reorienting outreach routes to reflect the realities of curfews and increasing the number of pills distributed at a time.

....A lot of people in the period of time made the decision to leave. And [name] tried to put herself in the position of each person and gave drugs so that a person could go somewhere abroad and not run in search of treatment every day. I tried to give for a month, for two, for three, so that there was a mandatory supply of medicines. I was more or less calm about people. The workload on social workers increased because people were afraid to go to a medical facility during the alarms. An additional, let's say, duty fell on us. There was an obligation not as social workers, but as people who provide help to positive people to send ART therapy.

The same participant goes on to detail how social workers went out of their way to figure out how to mail medications to their clients to ensure they had continued access to treatment:

There was a misunderstanding of how the Nova Poshta [a private courier service] works, there was a misunderstanding of how Ukrposhta [state services] works. There was a certain period of time when the Nova Poshta did not want to take medicines for transportation, for sending, so we had to look for those post offices that agreed to send these medicines. The workers were under a very, very heavy load, I would say.... (East)

NGO workers took on a similar approach to ensure that people who inject drugs had continued access to OST and transgender people continued to have access to HRT. Participants spoke of providing safety information for participants who might be travelling and transporting medicines, at risk to

themselves, under Russian invasion to ensure clients' access to necessary prescriptions was maintained.

I know for sure that they kept in touch with patients who were on the OST sites and with HIV-positive patients. Communication was maintained because the social work never ends, so you will support me that if the social support of the client has ended, this does not mean that the client has gone somewhere. He will call, communicate, sometimes he does not call the doctor, but calls the social worker, to ask him to go and find out the results of the tests, to go and help him with something else, all this remained.... (Center)

NGOs also maintained access to HIV pre-exposure prophylaxis (PrEP), HIV testing, naloxone, condoms and harm reduction supplies—demands for which increased among some clients— in order to maintain prevention efforts.

.... In addition, with Alliance [for Public Health], we have a direction on prevention, this is naloxone, which is in great demand. That is, when the war started, it was, well, a cry of the soul, because naloxone was nowhere to be found. The [city] factory was not working, most likely, and there was no way to buy it. Now everything is more settled, we are already... Because the war started—we dug up the remains wherever we could, looking for it. And we have clients, well, it is in great demand. This is their first medical aid while they wait for the ambulance. And every client wants to have an ampoule of naloxone with them. We have a project, that is, they are all informed how to use it, and well... it was in demand.... (Center)

Participants pointed to the response by frontline workers in maintaining access to HIV prevention and treatment as averting a potential rise in HIV transmission as expressed in the quotation below by a participant working in the eastern region of Ukraine:

Well, not anymore, because now harm reduction is working steadily, we are constantly organizing deliveries, and we quickly organized ourselves then. Well, I won't say that this is a large number of people who are infected, because, again, we quickly organized, there were social workers with their own cars who delivered distribution materials, delivered PrEP, delivered ART, and, so, the situation leveled off.... (East)

3.3 | Continuing to work despite a lack of adequate financial compensation

Throughout programme adaptations during the ongoing war, organizations continued to provide services despite working for outdated pay scales that did not adequately reflect their work, even prior to the onset of the war. As one participant stated: "Well, I don't know how to tell a person that he should sit for 8 hours a day, the whole week, for 6500 UAH [approx.

224 USD]". Participants spoke of the stress and burden that inadequate compensation added to their lives while they tried to maintain services during ongoing bombings and blackouts and without transportation and clean drinking water. Participants discussed the challenges to fulfil their work roles, burdensome reporting expectations from donors that continued throughout war, inadequate pay for frontline workers and the demoralizing effect this had on their work.

....To work for a social worker who can't earn her own bread. And other projects we can't give them. Well, we can give them something extra ... Well, we, for example, take a social worker, there is a minimum salary. We can't go any higher than that. You make the rate 10,000 [UAH, approx. 345 USD].... (South)

Participants spoke of delayed reviews of salary scales and outdated activity-based compensation that no longer reflects current realities. At a time when frontline workers are taking on additional work to support their clients, there is a demand to fairly compensate them for their service and a fear that it will be harder to engage frontline workers to continue to provide these types of services without adequate pay.

.... a person took everything he or she needed, left the house, spent money on travel, came to his or her job. And this is the person who is ready to provide a service. The person who is looking for clients, who spends time. And if, well, I'm more in favour of such a system, maybe a bonus system. Because I understand that this system scares a lot of people and makes them quit. I know people who, when they went from being great, cool social workers to quality social workers, who are focused on their work, they just left. Because they didn't see their value in it. And of course, if we take the system in general, and what is paid for in prevention programmes, we understand that a social worker does more. That is, we do a syphilis test there, but we never get paid for it. When we ask why, they say, "Well, you just take it as a workload, [it isn't] hard for you?" Well, a person does this work, he spends time on it. (National)

While participants continue to work despite these delays in payments, this also poses questions for prevention programme funding post war, when international donors again pull out and the government re-assumes responsibility for funding the HIV programme. Under the current condition of war, participants expressed concerns for the sustainability of staffing these services. As one participant stated:

...Yes, there are some projects left, or its prospects. And the prospects of it all are already kind of well...clear. That another year of these situations, a year of this war and the conditions of the real economic state of the country, m-m-m. ... Unfortunately, I do not think that we will have very many people willing to provide such services. (South)

4 | DISCUSSION

NGOs play a crucial role in service delivery for key population groups in Ukraine, particularly in the context of the ongoing war and displacement. These organizations serve as “first responders” in the HIV response [34], leveraging their proximity to communities, funders, and flexible models of practice to provide essential services and adapt to the changing conditions brought on by war. NGOs are often deeply embedded within the communities they serve, establishing trust and rapport with their clients. This closeness allows them to understand the specific needs and challenges faced by communities, tailoring their efforts accordingly. Particularly in the field of HIV prevention and treatment, these relationships prove invaluable, as they enable NGOs to reach individuals who may not otherwise have access to vital information and resources. Moreover, NGOs are characterized by their agility and innovation in service provision. They have the capacity to swiftly respond to emerging needs and adapt their programmes to address evolving circumstances, such as those created by war. In the context of Russia's war in Ukraine, NGOs have demonstrated remarkable resilience, adjusting their strategies to continue providing HIV prevention services amidst unimaginable disruptions.

However, it is impossible to ignore the impact that migration and ongoing conflict have on NGOs, affecting operational hours, the availability and location of services and staffing. Some organizations, previously operating region-wide, have restricted their services due to logistical challenges in areas affected by conflict. Medical supply disruptions and limitations in available healthcare services have further exacerbated these challenges, which are widespread across various sectors in Ukraine, influenced by the geographical proximity to war zones and the intensity of hostilities in the region. Despite these challenges, our study demonstrates that NGOs, through their “dense connections” [34, p.5] to people, other organizations, government and funders, find themselves positioned as “first responders”, adapting their services as best as possible. Our findings align with Friedman et al.'s work highlighting how NGOs providing HIV services immediately adapted their responses following the escalation to full-scale war in Ukraine, despite frontline workers also being impacted and, at times, displaced themselves [37]. Participants in our study recounted how their organizations worked to continue to make HIV prevention commodities and medicines available to key populations while expanding services to provide humanitarian aid to both clients and the wider community. Incredibly, some reports indicate increased enrolment in PrEP and some ART programmes in Ukraine since the start of the war [39, 40]. However, access to ongoing HIV treatment in occupied territories remains precarious, with a recent report indicating that ART access in the Donbas is now predicated on adopting a Russian passport—a condition that nearly half of PLHIV in the region are loathe to accept [41].

Despite the important role played by frontline workers, they remain underpaid, often volunteering their time while placing their own lives and mental health at risk. Our findings point towards how overworked and under-resourced organizations across Ukraine continue to mobilize supports under extraordinary conditions. We wholeheartedly echo

Roels et al.'s assertion that sustainable funding for organizations “are actually investments in disaster preparedness” and that “city/state governments should recognize the work of community organizations, learning that social support and collective care cannot occur without the pre-existing structures that are well-embedded and trusted within communities” [34, p.14].

We further stress the importance of including NGO representatives in important policy conversations at local, regional and national levels, as they contribute invaluable contextual and experiential knowledge and are best situated to understand the needs of their communities. During the war, we have seen how NGOs expanded their service delivery beyond their clients to respond to the needs of entire impacted communities. While we do not often turn to key population NGOs as first responders in humanitarian crises, their inherent adaptiveness is ideally suited to assume this role, as they hold important insights on community needs and movements, especially among the most marginalized populations [34, 40].

Critical questions remain around the sustainability of this current situation. How long will frontline workers be able to provide supports without adequate compensation for their work, which has only grown since the war? While further financial supports are urgently needed for frontline workers, ongoing, stable funding will be critical following the war. While currently recognizing the uncertainty of the postwar period, we maintain that there will be an urgent need for social and health services provided by NGOs and frontline workers [37]. We argue that the voices of frontline workers should be heard at policy- and programme-planning tables to help rebuild communities affected by war, as well as to ensure that HIV care, harm reduction, HRT and other essential services for key populations are maintained.

4.1 | Limitations and strengths

Our findings are based on key informant interviews and may not be generalizable to the experiences of all those working in NGOs in Ukraine. As these were key informant interviews, we did not collect detailed demographic data. However, our representation from those working in NGOs across the country, including in territories facing occupation, ensured that we are presenting a wide range of experiences. As our interviews occurred a year into the war, responses might be subject to recall bias. However, the incredibly sensitive nature of the discussions and our previous research relationships allowed for an opportunity to explore how NGOs responded to and adapted their services.

5 | CONCLUSIONS

NGOs in Ukraine play a vital role as responders during structural shocks, such as war, adapting their services to meet the emergent needs of affected communities. There is an urgent need to support Ukrainian NGOs with adequate resources for key population service delivery—including HIV prevention and treatment—to facilitate a responsive and community-centred approach. NGOs' ability to operate closely with affected populations, coupled with their adaptability in the face of

adversity, underscores their indispensability in safeguarding health, particularly in times of crisis.

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COMPETING INTERESTS

The authors declare that they have no competing interests.

AUTHORS' CONTRIBUTIONS

All authors supported the design of the study. DP, AG and TT collected the data. LL and LMM conducted the analysis. LL, LLM and NH wrote the first draft of the manuscript. All authors reviewed and approved the final version of the manuscript.

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DATA AVAILABILITY STATEMENT

As the datasets involve sensitive data from criminalized and stigmatized groups, data will not be made publicly available. Some data may be made available from the corresponding author on reasonable request and approval from the NGOs and study team.

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RESEARCH ARTICLE

An implementation evaluation of the Breaking Down human rights barriers to HIV services initiative in Ukraine

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Abstract

Introduction: Globally, stark inequities exist in access to HIV treatment and prevention. The eastern European and central Asian region is experiencing the sharpest rise in new HIV acquisition and deaths in the world, with low rates of treatment and prevention services, especially for key and vulnerable populations who face a range of human rights-related barriers to HIV prevention and treatment.

Methods: An implementation learning evaluation approach was used to examine the implementation of the Breaking Down Barriers initiative targeting key and vulnerable populations in Ukraine. Between September 2022 and April 2023, researchers conducted 23 key informant interviews with individuals from the Ukrainian government, implementing organizations and human rights experts. Using a concurrent triangulation design, researchers and key informants, in a process of co-creation, sought to describe programme accomplishments, challenges and innovations in implementation, between 2021 and 2023, including periods before and after Russia's February 2022 full-scale invasion.

Results: Eight rights-based interventions related to HIV were identified in Global Fund programme documents and key informant interviews as making up the core of the Breaking Down Barriers initiative in Ukraine. These included programmes seeking to: eliminate stigma and discrimination; ensure the non-discriminatory provision of medical care; promote rights-based law enforcement practices; expand legal literacy ("know your rights"); increase access to justice; improve laws, regulations and policies; reduce gender discrimination, harmful gender norms and violence against women and girls; and mobilize communities for advocacy. These programmes received US\$5.9 million in funding. Key informants reported that significant progress had been made addressing human rights barriers and scaling up interventions, both before and after Russia's invasion. Programme implementors adopted innovative approaches, including using paralegals, hotlines and other community-led interventions, to ensure that key and vulnerable populations, including displaced individuals, were able to access prevention and care.

Conclusions: An implementation learning evaluation approach examining programmes addressing human rights barriers to HIV services, designed as a process of co-creation between researchers, programme implementors, government officials and human rights experts, can provide a robust assessment of programme outputs, outcomes and evidence of impact, despite a challenging operational environment.

Keywords: HIV; TB; human rights; stigma; discrimination; key populations

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1 | INTRODUCTION

Since 2010, the eastern Europe and central Asian region has experienced the sharpest rise in new HIV acquisitions and deaths in the world, with a 49% increase in HIV acquisitions and a 46% increase in AIDS-related deaths [1]. With an estimated 250,000 people living with HIV (PLHIV), Ukraine has the second largest HIV epidemic in the WHO European Region [2]. The epidemic is concentrated in key populations, with an HIV prevalence of 20.3% among people who inject

drugs, 3.1% among female sex workers and 3.9% among men who have sex with men [2–4].

Russia's full-scale invasion of Ukraine on 24 February 2022 profoundly changed all aspects of life for the country's 43 million people. More than 6 million people fled abroad, and millions more relocated internally [5, 6]. Many government services came to a halt, as did the economy [7]. The invasion had a major impact on Ukraine's delivery of healthcare: health facilities suddenly had to care for wounded soldiers and civilians; healthcare workers faced the difficult choice of

staying or fleeing; health facilities were repurposed for non-medical use; civilian patients in Russian occupied zones were forcibly evicted from health facilities or denied access to care; and medical supplies were requisitioned by Russian forces [8]. From the start of the invasion to the end of 2022, WHO recorded 790 attacks on health facilities [9]. By the end of 2023, the number of attacks had nearly doubled [10].

HIV programmes in Ukraine were significantly affected by the conflict [11–13]. PLHIV were displaced to areas of Ukraine that traditionally had low HIV prevalence and where the capacity of HIV services was insufficient [14]. Thousands of people were cut off from treatment and prevention services, including opioid substitution treatment (OST), which is banned in Russia [15–20]. Transgender women faced challenges leaving the country if their identification documents did not match their gender identity [21].

Since 2017, as a part of the Breaking Down Barriers initiative of the Global Fund, Ukrainian organizations have implemented HIV-related human rights programmes which seek to increase access to prevention and treatment services for key and vulnerable populations. The Breaking Down Barriers initiative provides technical and financial support for the implementation of rights-based HIV, tuberculosis (TB) and malaria interventions in 24 countries. These include programmes aimed at addressing stigma and discrimination and ensuring people-centred healthcare and law enforcement practices, as well as programmes aimed at mobilizing communities and increasing legal literacy and access to justice [22]. This implementation learning evaluation examined the implementation, outputs and outcomes of the Breaking Down Barriers initiative, focusing on the period between 2021 and 2023, before and after Russia's invasion, and in comparison with data from previous periods (2017–2020).

2 | METHODS

The evaluation of the Breaking Down Barriers initiative in Ukraine used an implementation learning approach drawing on a document review of programme monitoring documents alongside key informant interviews with implementers, government officials and human rights experts. While the assessment focused upon the scope, scale and quality of human rights programmes and their outcomes, as well as priorities for future investment, attention was also paid to national ownership, enabling environments and community-led responses.

An implementation learning evaluation is an approach to multi-organization assessment, typically incorporating qualitative and quantitative data related to implementation processes while also assessing changes in the broader context (such as the legal and policy environment). The approach seeks to facilitate quality improvement and identify recommendations for increased programme effectiveness. For our evaluation, we adapted the implementation learning evaluation principles outlined by Balasubramanian et al., focusing upon three steps: (1) gathering data on operational decision-making by implementing organizations related to scale up of programmes; (2) collecting process and outcome data for each implementation objective; and (3) assessing multi-level context-

tual factors that affected the implementation process, outputs and outcomes [23]. Two other domains related to our evaluation, programme quality and recommendations for future programme investment, are reported elsewhere [24].

Recognizing that conducting an evaluation of programme efforts amidst a war would be a challenge, we sought to orient the evaluation as a process of co-creation with key informants [25]. Together, we pursued not only a greater understanding of implementation processes and outcomes, but, critically, the development of a consensus among implementors and government actors of priority areas for future investment. This approach also reflects efforts to decolonize and disrupt traditional evaluation research practices and reporting [26].

As a first step of the evaluation, three external evaluators (DL, YK and JJA) provided an overview of the objectives of the evaluation at a meeting convened by the Country Coordinating Mechanism (CCM) overseeing Global Fund activities in the country. Following the meeting, 23 programme implementers, government officials and independent human rights experts were identified as potential key informants, based upon recommendations from the CCM and from the leadership of individual implementing organizations participating in the Breaking Down Barriers initiative.

Potential key informants were provided with an explanation of the evaluation objectives and approach, and of the expectation of their involvement as experts and active participants in the evaluation process, helping to define key questions and contextualizing outputs, outcomes, facilitating factors and challenges in implementation. Consistent with the co-creation approach, potential key informants were asked if they would consent to having their comments identified; however, they were also assured that they could provide comments without attribution.

All individuals who were asked agreed to participate and provided verbal consent, including individuals representing 16 different institutions: 100% Life, the Alliance for Public Health, the Public Health Center, Alliance Global, Ukrainian Network of People with Drug Dependence (VOLNA), Ukrainian Network of Women Who Use Drugs (VONA), FreeZone, Cohort, Legalife-Ukraine, Ministry of Health, Ukrainian Prison Service, Hope & Trust, Ukrainian Helsinki Union for Human Rights, Ukrainian Legal Aid Foundation, Positive Women and TB People.

Semi-structured interviews were conducted in-person and remotely, using video, between September 2022 and April 2023. Interviews were conducted by fluent Ukrainian and Russian speakers, and lasted between 30 and 90 minutes. Documents reviewed included reports from programme implementers; Global Fund performance letters and briefing notes; national HIV strategy documents and human rights plans; specific key population or sector documents; UN Agency reports; donor implementation maps; integrated biobehavioural surveillance reports; and financial investment reports.

Researchers used a concurrent triangulation design to analyse information from the document review and key informant interviews in collaboration with key informants. Key results were first analysed broadly, according to the categories of intervention objectives defined by the Global Fund, examining the similarities and differences across different implementing

organizations. Key challenges and facilitating factors were analysed using thematic data analysis approaches following Castleberry and Nolen [27]. Preliminary results were shared in several meetings with representatives from organizations participating in the evaluation. Feedback was incorporated in the preparation of the final results. Where information or observations regarding a specific intervention was provided by a single key informant, the informant is indicated, but, consistent with the objective of the co-creation process, in most cases, challenges and outcomes were endorsed by multiple informants and by consensus in the feedback discussions. In these cases, no specific informants are indicated.

The protocol (2002007637) for the Breaking Down Barriers evaluation was reviewed by the Drexel University Office of Research's Institutional Review Board and, consistent with Center for Disease Control and National Institutes of Health guidance, was determined to be not human subjects research [28, 29].

3 | RESULTS

Eight rights-based HIV intervention objectives were identified in the Global Fund programme documents and by key informant interviews as the core of the Breaking Down Barriers initiative. These objectives included: (1) eliminating stigma and discrimination; (2) ensuring non-discriminatory provision of medical care; (3) promoting rights-based law enforcement practices; (4) expanding legal literacy ("know your rights"); (5) increasing access to justice; (6) improving laws, regulations and policies; (7) reducing gender discrimination, harmful gender norms and violence against women and girls; and (8) mobilizing communities for human rights advocacy. To support the implementation of activities addressing these objectives, Ukraine received US\$5.9 million from the Global Fund. Of the eight objectives, the greatest funding was given to programmes addressing law enforcement practices and community mobilization and advocacy, and the least funding was provided to programmes reforming laws, regulations and policies (Table 1).

3.1 | Eliminate stigma and discrimination

Ukraine has implemented a wide variety of programmes to address stigma and discrimination in multiple contexts, including in community, healthcare and law enforcement settings. For example, the Alliance for Public Health engaged journalists on drug policy issues, creating balanced narratives around people who use drugs. Implementing organizations used International Drug Users Day (1 November) and World AIDS Day (1 December) for awareness raising, and the release of the HIV Stigma Index drew attention to HIV stigma in the media and among health professionals. Key informants reported that these activities allowed for high-profile, public, discussion of the human rights of PLHIV and key populations.

Key informants and programme reports also noted that a wide range of programmes aimed at reducing self-stigma were implemented, including information sessions that combined "know-your-rights" information and discussion of access to justice with information on stigma and discrimination. For example, Legalife-Ukraine, a community-based organization of

sex workers, organized trainings for 320 sex workers in 2020 and 551 sex workers in 2021 (Interview with Natalia Isayeva, Legalife-Ukraine).

Other community organizations sought to address stigma and discrimination by creating new digital tools. FreeZone created the FreeLife app as a comprehensive information resource for current and former prisoners that included information on human rights and access to HIV prevention and treatment services. The application also allows users to file complaints and seek legal support in case their rights have been violated (Interview with Olga Karpenko and Nikolay Kukarkin, FreeZone).

Key informants discussed efforts to address the legal barriers that lead to stigma and discrimination. In particular, the parliamentary expert platform "Fight for Health" was identified as an important forum for the discussion of amendments to laws that criminalize HIV acquisition and exposure to HIV. The platform has also sought to codify access to testing, diagnosis, treatment, pre-exposure and post-exposure prophylaxis in Ukraine's healthcare legislation and HIV law, and to draft laws legalizing sex work [30]. Advocacy for these changes was initially suspended due to Russia's invasion but relaunched in the second half of 2022.

Key informants also described how community organizations have worked to raise awareness among religious communities and organizations to increase tolerance towards HIV-vulnerable groups, targeting all major faith groups in Ukraine, including the Ukrainian Orthodox Church, the Ukrainian Greek Catholic Church, Muslim communities and Protestant churches [31].

3.2 | Ensure non-discriminatory provision of medical care

Annual programme reports indicated that, as a part of efforts to reduce discrimination in healthcare, 217 trainings of healthcare professionals were conducted, reaching 1652 nurses and 1582 medical doctors between 2020 and 2022. Key informants reported that one outcome of these efforts were their integration into routine trainings for health workers, including for primary care providers who following Ukraine's healthcare reform play a key role in providing care for key and vulnerable populations (Interview with Rachinska Valeria, 100% Life).

Similarly, in 2021, the Ukrainian government's Public Health Centre began integrating materials on human rights and medical ethics into continuing education programmes available on its website for healthcare providers. Materials related to patient-centred care and stigma and discrimination were included in family medicine modules and material on community mobilization, communications and advocacy were included in its public health course. More than 135,000 users have received certificates for completing its online course on HIV, TB and key populations (Interview with Serhiy Myroniuk, Public Health Center).

Stigma and discrimination were also addressed in 100% Life Network's "Your Family Doctor" campaign which reached more than 2000 doctors between 2021 and 2023. The Alliance for Public Health conducted trainings of health workers on the provision of OST, expanding the number of trained healthcare workers from 177 to 460, and trained

Table 1. Investments, implementing organizations and activities to remove human rights-related barriers to HIV services by intervention objective (2021–2023)

Intervention objective	Investment	Implementing organizations	Activities
Eliminate stigma and discrimination	\$ 390,272	100%, APH, PHC, AG, VONA, PW, KG, LU	Media campaigns to reduce HIV-related stigma and discrimination. Training of journalists; raising awareness among religious communities about HIV and stigma towards key and vulnerable populations; stigma index studies
Ensure non-discriminatory provision of medical care	\$ 335,366	100%, PHC, APH, KG, H&T, LU	Trainings on HIV-related stigma and discrimination for healthcare workers at all levels of care; hotlines; documentation systems
Promote human rights-based law enforcement practices	\$ 1,559,819	APH, LU, FZ	Training law enforcement about HIV prevention, harm reduction and substitution treatment
Expand legal literacy ("know your rights")	\$ 394,681	100%, APH, VOLNA, VONA, LU, TPU, AG, KG, FZ, PW, TU, ULAF, UHHRU, 100%	Peer paralegals empower community members to know and defend their rights; community training sessions; digital applications with information on HIV, including on rights and legal recourse
Increase access to justice	\$ 798,428	100%, APH, VOLNA, VONA, LU, TPU, AG, KG, FZ, PW, TU, ULAF, UHHRU, H&T	Peer paralegals, community training sessions; digital applications; hotlines; referral to free legal aid services; human rights documentation systems
Improve laws, regulations and policies	\$ 161,171	100%, APH, TPU	Fight for Health platform; human rights documentation systems
Reduce gender discrimination, harmful gender norms and violence against women and girls	\$ 795,407	100%, APH, VOLNA, VONA, LU, TPU, AG, KG, FZ, PW, TU, ULAF, UHHRU	Gender-specific programmes by women's and LGBT groups, paralegal programmes, hotlines, human rights documentation systems
Mobilize communities for human rights advocacy	\$ 1,496,834	100%, APH, VOLNA, VONA, LU, TPU, AG, KG, FZ, PW, TU, ULAF, UHHRU	Paralegal programmes, human rights documentation, gender-specific programmes
Total	\$ 5,931,978		

Abbreviations: 100%, 100% Life; AG, Alliance Global; APH, Alliance for Public Health; FZ, FreeZone; KG, Cohort; LU, Legalife-Ukraine; H&T, Hope and Trust; PHC, Public Health Center; PW, Positive Women; TPU, TB People Ukraine; TU, Teens Ukraine; UHHRU, Ukrainian Helsinki Human Rights Union; ULAF, Ukrainian Legal Aid Foundation; VOLNA, Ukrainian Network of People who Use Drugs; VONA, Ukrainian Network of Women who Use Drugs.

"transgender-friendly" doctors and multidisciplinary teams serving transgender individuals in five regional centres (Interview with Pavlo Skala, Alliance for Public Health).

3.3 | Promote rights-based law enforcement practices

Interventions conducted by the Alliance for Public Health and Legalife-Ukraine sought to reduce stigma and increase respect for human rights through work with law enforcement officials. For example, Legalife-Ukraine trained 3872 law enforcement officers in 2020 on human rights (Interview with Natalia Isayeva, Legalife-Ukraine). The Alliance for Public Health's work with law enforcement officials increased from small-

scale programmes in 2017 to trainings in 18 regions in 2020 and 21 regions in 2021. However, in 2022 following Russia's invasion, key informants noted that high turnover rates among police officers, many of whom joined the Ukrainian armed forces, posed a challenge, interrupting the continuity of programmes and requiring the development of new relationships of trust (Interview with Pavlo Skala, Alliance for Public Health).

3.4 | Expand legal literacy ("know your rights")

A variety of approaches for improving legal literacy were implemented, including the use of traditional print materials, websites, phone apps, chatbots, telephone hotlines,

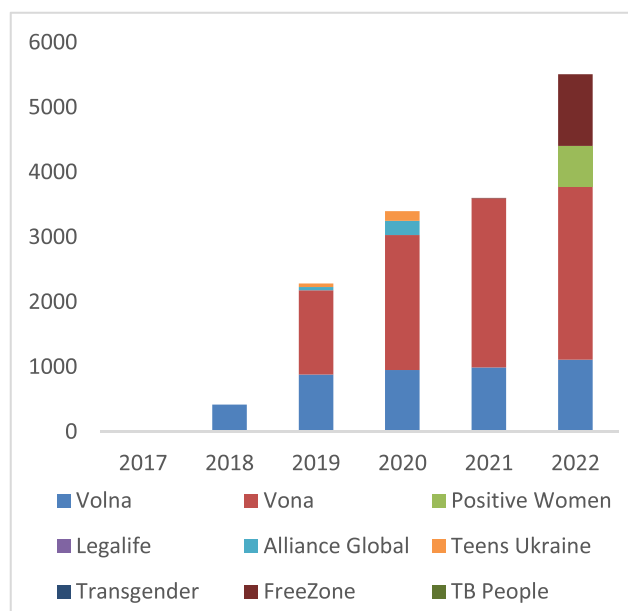


Figure 1. Paralegal consultations by year. Abbreviation: TB, tuberculosis.

informal legal literacy gatherings and sharing of rights information at health services providers. Figure 1 shows the dramatic increase in the number of individuals reached by paralegal programmes, run by nine different organizations and targeting different populations, between 2017, when no paralegal programmes existed, and 2022 when 5510 consultations took place.

By contrast, hotline consultations were largely stable between 2017 and 2021, until a surge in calls occurred after Russia's full-scale invasion of Ukraine in 2022 (Figure 2). Hotlines provided a number of different services: they anonymously offer callers basic information about HIV, other sexually transmitted infections, and drug dependence; orient or link them to HIV or drug-related services; and register and act on complaints about violations of their human rights.

3.5 | Increase access to justice

Once individuals are aware of their rights, access to justice programmes help people seek redress from rights violations. Between 2017 and 2023, paralegal programmes serving key and vulnerable populations dramatically increased their geographic coverage (Figure 3). Three of the paralegal networks (Legalife-Ukraine, Positive Women and VONA) focused specifically on the needs of women, while FreeZone worked with individuals in detention. Datacheck, run by 100% Life and the REAct programme, run by the Alliance for Public Health, are similar to the paralegal programmes, working to monitor and respond to human rights violations at the community level, for example in the case of REAct, using "reactors," social workers, project coordinators and other non-governmental organization staff working with key and vulnerable populations, to provide information on rights, document violations and help provide redress. The REAct programme expanded from 11

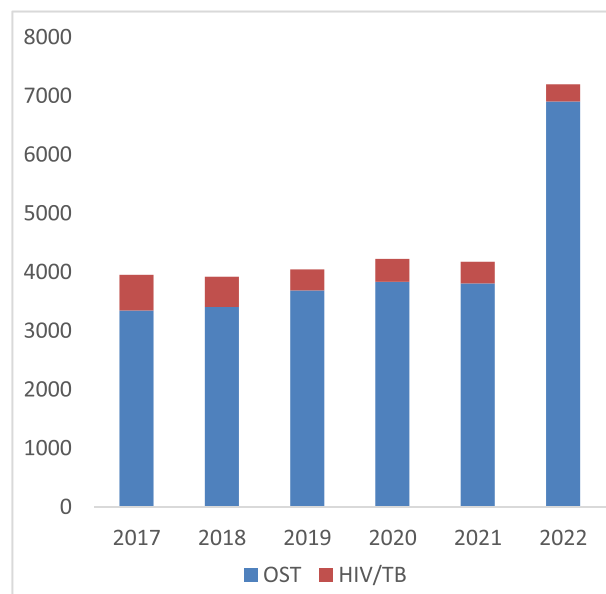


Figure 2. Hotline consultations by year. Abbreviations: OST, opioid substitution treatment; TB, tuberculosis.

regions in 2020 to 17 in 2022 (Interview with Pavlo Skala and Oksana Pashchuk, Alliance for Public Health). Both types of programmes reported high percentages of resolved claims, a key outcome, with 68% for 100% Life's Datacheck and 89% for REACT in 2022.

3.6 | Improve laws, regulations and policies

There was widespread agreement among key informants that community-based or -led monitoring efforts to reform laws, policies and practices are among the most developed and impactful programmes addressing HIV in Ukraine. Between 2021 and 2023, key and vulnerable population communities prioritized both short- and long-term advocacy goals. While Russia's full-scale invasion of Ukraine negatively affected these programmes significantly, the European Union accession process created opportunities as Ukraine committed to align itself with European Union standards.

Advocacy also addressed implementation and policy challenges. For example, Volna used community-led monitoring to prevent late delivery of OST and treatment interruptions, facilitating medicines procurement for 8125 patients. 100% Life and other civil society organizations advocated for greater state and local funding for the HIV response. Community-based organizations used information campaigns, patient mobilization and direct advocacy with decision-makers, and involved outside experts. This work significantly strengthened the role of communities and enhanced engagement with public authorities, which increasingly saw them as partners.

3.7 | Reduce gender discrimination, harmful gender norms and violence against women and girls

Key informants reported increased geographic coverage of programmes addressing gender discrimination, including, for

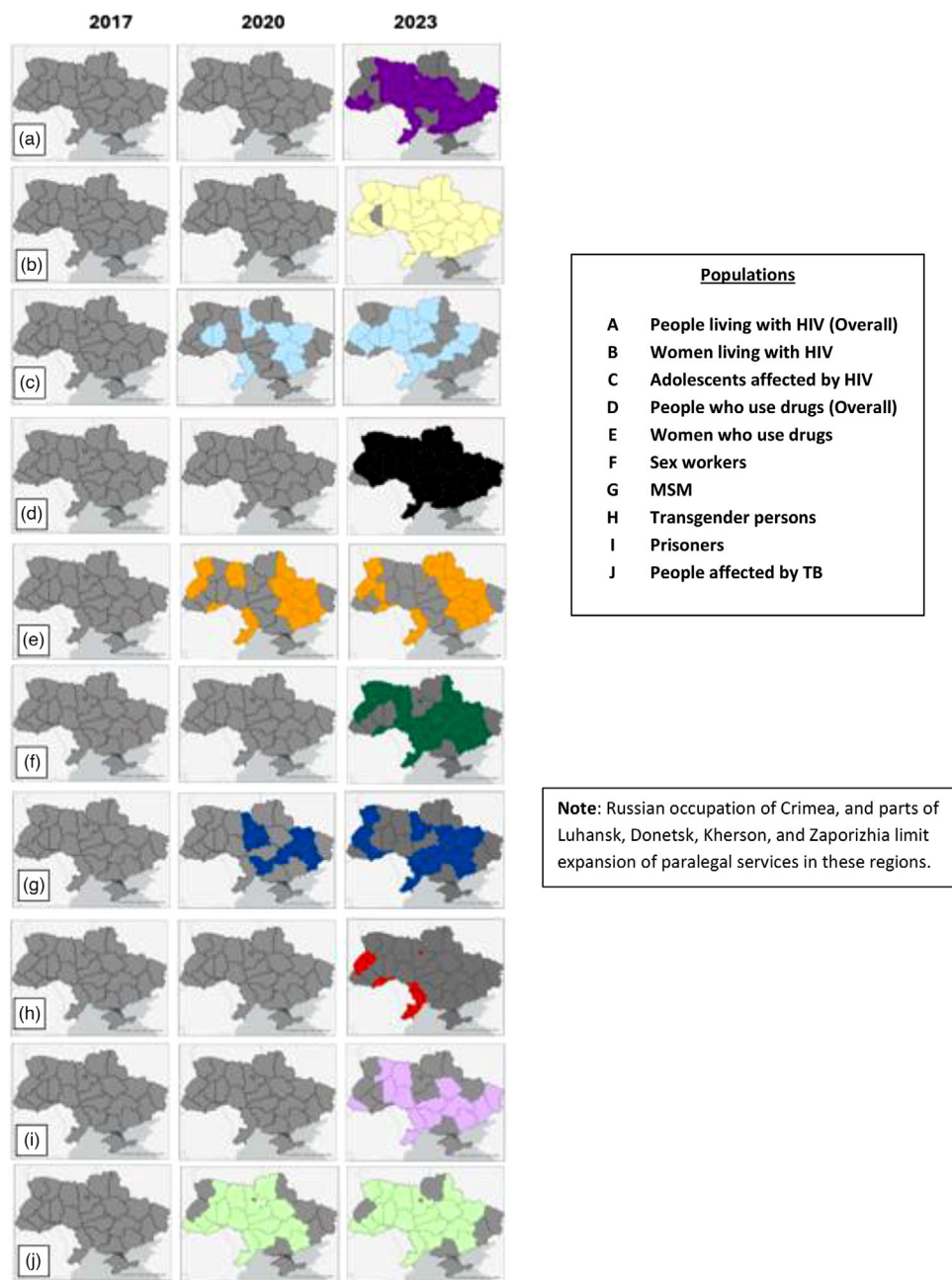


Figure 3. Expansion of paralegal service by region and population (2017–2023). Abbreviations: MSM, men who have sex with men; TB, tuberculosis.

example, initiatives to ensure that transgender people and women who use drugs are able to access networks of “friendly doctors,” including gynaecologists, venereologists and infectious disease specialists. For example, regional coordinators of the organization “Positive Women” created a database of doctors who provide non-discriminatory care.

Positive Women also engaged in advocacy with health-care officials for new clinical guidance for pregnant women living with HIV. Vona’s advocacy at regional levels resulted in the expansion of healthcare providers who are knowledgeable about, and friendly to, women who use drugs.

Cohort advocated successfully for the establishment of a special service in Kyiv to provide transgender-specific care.

Programmes to assist victims of gender-based and domestic violence were also significantly expanded, especially in response to the COVID-19 pandemic. Following Russia’s invasion, key informants said that the need for gender-based violence services has grown significantly, posing a new challenge for the government and civil society organizations and making linking to sexual and gender-based violence services of humanitarian clusters a key challenge.

3.8 | Mobilize communities for human rights advocacy

Ukrainian PLHIV organizations have a long history of mobilizing communities and conducting human rights advocacy. At the start of the Breaking Down Barriers initiative, key informants said that Global Fund principal recipients made a conscious choice to invest in community-led organizations, including key population organizations that were less established. Key informants said that this strategy was showing results with dramatically expanded regional coverage. This allowed them to quickly and effectively respond to Russia's full-scale invasion, linking significant numbers of people to access to HIV prevention and treatment services.

4 | DISCUSSION

Before Russia's full-scale invasion, Ukraine had made significant progress towards addressing stigma. Ukraine's PLHIV Stigma Index studies, conducted in 2010, 2013, 2016 and 2020, found consistent decreases in stigma over time for most indicators, including, for example, a decrease in "gossip" related to HIV status (from 30% in 2010 to 8% in 2020) and unauthorized disclosure of HIV status (from 37% in 2010 to 18% in 2020) [32]. Progress too was seen in attaining the UNAIDS 95-95-95 targets (representing the percentage of PLHIV knowing their HIV status, the percentage of those on sustained treatment and the percentage of those attaining viral suppression). These indicators were 75-83-94 in 2021 as compared to 56-72-89 in 2017 [33]. However, further progress towards these targets has been hampered by the Russian invasion and subsequent humanitarian crisis, which has also prevented further Stigma Index studies [34]. Responding to the challenges of Russia's invasion, programme implementers took actions to strengthen the resiliency of programmes; ensure greater engagement of key and vulnerable populations to identify and defend human rights issues; and took advantage of opportunities to conduct advocacy for legal and policy change.

4.1 | Resiliency of programmes

Evidence from the 2022 to 2023 assessment found numerous examples of resiliency in the implementation and scale up of rights-based HIV programmes. The number of mechanisms for key and vulnerable populations to seek access to remedies has dramatically increased despite the war. Paralegals, hotline operators and owners of mobile applications have all been trained to provide primary legal aid to clients, and to refer them to professionals if secondary or tertiary legal aid is required. Efforts to link community human rights mechanisms to Ukraine's free legal aid services have secured the eligibility of key and vulnerable populations and focus on training of legal aid coordinators.

4.2 | Readiness to demand and defend rights

Thousands of members of key and vulnerable populations have reported violations of their rights to community-led monitoring and documentation initiatives, demonstrating both

an awareness of their rights and a willingness to report violations. Moreover, since the Russian invasion, the number of inquiries and complaints from key and vulnerable populations have significantly increased, forcing, among others, the OST and Drug Dependence Hotline to increase their operating hours, and establish new channels of communication to meet the demand for information and help ensure clients' continued access to health services.

4.3 | Improving the legal and political environment

Significant improvements in the legal environment for key and vulnerable populations facilitated the implementation of all intervention programmes. However, the single most significant legal barrier, the criminalization of people who use drugs, and aspects of sex work, persists. Nonetheless, improvements to the legal environment included: changes to the HIV Law (2023); changes to regulations for take-home doses of OST (2022); the removal of legal provisions banning men who have sex with men from becoming blood donors (2021); and the decision to transfer the prison healthcare system from the Ministry of Justice to the Ministry of Health (2021).

Overall, these legal changes have improved access to treatment for PLHIV and people who use drugs by removing discriminatory legal provisions and reducing HIV-related stigma and discrimination. Several further amendments to key laws affecting key and vulnerable populations are currently pending before Ukraine's parliament. These amendments, including the decriminalization of transmission of HIV and the recognition of same-sex partnership, were drafted with active participation of community organizations through the Parliamentary Platform.

Several limitations should be recognized. First, conducting an evaluation amidst a war is a challenging process. Russia's attacks on Ukraine's electrical grid repeatedly disrupted interviews. Many key informants faced emergencies related to the war that took precedence over interviews with the evaluation team. Second, the evaluation relied significantly upon programme reports and the perspectives of programme implementers. Given the ongoing war, it was not feasible to include the perspectives of programme beneficiaries.

Despite these limitations, the implementation learning evaluation method, using a co-creation approach, engaged key stakeholders, who had long-term experience and perspective in the implementation of diverse rights-based programmes, and who felt ownership in the evaluation process and its ultimate goal of contributing to decisions on future investment.

5 | CONCLUSIONS

The results of our evaluation found that Ukrainian organizations were successfully scaling up and adapting programmes addressing stigma and discrimination in communities and health settings; working to address harmful laws and police practices and increase legal literacy and access to justice; reducing gender discrimination and violence; and mobilizing communities affected. Ukrainian organizations responded resiliently to challenges, finding innovative solutions to reach those displaced and to ensure the continuity of HIV programmes.

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COMPETING INTERESTS

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AUTHORS' CONTRIBUTIONS

JJA, DL and YK designed the evaluation approach. DL and YK conducted the field research in collaboration with key participants. VR, PS and SM were key informants. All authors contributed to the data analysis. JJA and DL wrote the first draft of the manuscript. All authors contributed to subsequent revisions and approved the final submission.

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DATA AVAILABILITY STATEMENT

Additional data are available in the full evaluation report: <https://www.theglobalfund.org/en/throughout-the-cycle/community-rights-gender/>

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SHORT REPORT

Patterns of daily oral HIV PrEP adherence among people who inject drugs in Ukraine: an analysis of biomarkers

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Abstract

Introduction: Daily oral HIV pre-exposure prophylaxis (PrEP) with tenofovir/emtricitabine (TDF/FTC) is recommended for people who inject drugs (PWID) but coverage is low. The real-life effectiveness of PrEP among PWID is unknown as previous studies were conducted in controlled settings and mainly relied on self-report. Analysis of PrEP metabolites—tenofovir diphosphate (TFVdp) and emtricitabine triphosphate (FTCtp)—offers an objective measure of adherence.

Methods: To analyse longitudinal patterns of PrEP adherence among PWID in Ukraine, we used data from a community-based implementation trial conducted in Kyiv between July 2020 and March 2021 to test the efficacy of SMS reminders to improve adherence. Among 199 enrolled participants, 156 (78.4%) were retained through 6 months. Based on TFVdp/FTCtp levels assessed at 3 and 6 months, we identified groups with various adherence patterns (adherent at ≥ 2 doses/week, improved, worsened, non-adherent). Correlates of adherence were analysed using multinomial logistic regression.

Results: Most participants (53.8%, $n = 84/156$) had no detectable metabolites at both assessments; 7.1% ($n = 11/156$) were consistently taking ≥ 2 doses/week; 1.3% ($n = 2/156$) were consistently taking ≥ 4 doses/week; 13.5% ($n = 21/156$) exhibited improved and 21.8% ($n = 34/156$) had worsened adherence at 6 compared to 3 months. "White coat compliance" (increased dosing prior to assessment) was common. Consistent adherence was associated with SMS reminders, younger age, employment, lower income, longer injection drug use duration, recent high-risk injecting (receptive syringe sharing, using pre-filled syringe, back- or front-loading, container sharing), absence of overdose in the past 6 months, perceived HIV risk through sexual intercourse and higher PrEP self-efficacy. Alcohol consumption was associated with inconsistent PrEP use. Groups with improved and worsened adherence did not differ.

Conclusions: Daily oral PrEP may not achieve the desired effectiveness among PWID as a standalone intervention, calling for testing of alternative PrEP formulations and innovative integrated risk reduction strategies, especially in the context of HIV epidemics associated with injection drug use in eastern Europe and central Asia and the public health crisis in Ukraine caused by the war with Russia. SMS reminders may be effective among PWID who prioritize PrEP. Our findings offer practical guidance in identifying PWID who are likely to benefit from PrEP and those who need additional support.

Keywords: tenofovir; emtricitabine; tenofovir diphosphate; emtricitabine triphosphate; dried blood spot; biomarkers

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1 | INTRODUCTION

Daily oral pre-exposure prophylaxis (PrEP) with tenofovir/emtricitabine (TDF/FTC) is an important component of the HIV prevention toolkit, with efficacy demonstrated among all key populations [1, 2]. Despite the recommendations to prescribe PrEP to people who inject drugs (PWID), coverage remains low, services are often unavailable and national policies are lacking [3–8]. Evidence of real-life PrEP effectiveness among PWID is limited [3–5]. Monitoring of PrEP adherence that is key to its effectiveness is challenging as traditional

measures are often inaccurate [9–11]. Recent advances in the development of biomarkers, including unique pharmacokinetic profiles of PrEP metabolites tenofovir diphosphate (TFVdp) and emtricitabine triphosphate (FTCtp), allow objective and more accurate measurements of adherence [11–14] compared to traditional measures. A combination of the two metabolites reduces misclassification compared to each metabolite alone [15].

After the Bangkok Tenofovir Study, only three studies analysed PrEP adherence among PWID using biomarkers [16–18]. These studies found low adherence and low validity of

self-reported PrEP compliance, but little is known about the patterns and dynamics of adherence and factors associated with PrEP uptake in this population [3, 6], in particular in settings with HIV epidemics concentrated in PWID communities. In Ukraine—one such setting [19–22]—PrEP has been available since 2017, and national guidelines recommend daily dosing. However, in 2021, 828 PWID were receiving PrEP corresponding to an estimated 0.3% of HIV-negative PWID [23]. In this study, we analyse data from the PrEP adherence intervention trial conducted in Kyiv, Ukraine [18], to explore patterns and correlates of PrEP adherence among PWID over time.

2 | METHODS

2.1 | Study design

The detailed methodology of the parent study was described previously [18]. An implementation trial among 199 PWID was conducted between July 2020 and March 2021 to test the efficacy of SMS reminders in improving PrEP adherence. Participants were recruited by outreach workers of community harm reduction programmes. Consented participants completed structured surveys and provided blood samples (used for dried blood spot [DBS] and HIV testing) at baseline and at 3- and 6-month visits.

2.2 | Measurement and interpretation of PrEP metabolites (TFVdp/FTCtp)

Details of the DBS sample collection, storage and analysis have been published [18]. The lower limit of quantification was 100 fmol/punch for both metabolites. We used the TFVdp threshold of ≥ 700 fmol/punch to indicate ≥ 4 doses/week on average over the past 2–3 months [9]. The interpretation of TFVdp/FTCtp level combinations in DBS was based on pharmacokinetic modelling [15] and population pharmacokinetic studies [12, 13].

2.3 | Dynamics of PrEP adherence

Based on the changes of TFVdp/FTCtp concentrations between 3- and 6-month assessments (Figure 1), we defined the dynamics of adherence as follows:

Consistent non-adherence: undetectable levels (cell A) at both assessments.

Worsened adherence: transition to undetectable levels (cell A) at 6-month from any other cell at 3-month, or transition from consistent intake of ≥ 2 doses/week at 3-month (cells E/F/H/I) to any other cell at 6-month.

Improved adherence: transition from undetectable levels (cell A) at 3-month to any other cell at 6-month, or transition to a consistent intake of ≥ 2 doses/week at 6-month (cells E/F/H/I) from any other cell at 3-month.

Consistent adherence: any transitions indicating consistent intake of ≥ 2 doses/week (cells E/F/H/I).

Mixed adherence: all other transitions, for example between cells B and D.

2.4 | Statistical analysis

Associations between the patterns of PrEP adherence dynamics (consistent non-adherence, worsened, improved and consistent adherence) as an outcome and potential correlates were analysed in the R computing environment [24] using multinomial logistic regression [25]. Covariates included demographics and relevant survey measures [2, 3, 10, 26] accounting for heterogeneity in covariate distributions [18].

2.5 | Ethics statement

The study protocol was approved by the Ukrainian Institute on Public Health Policy IRB#1 (#2020-009-02). All participants provided informed consent.

3 | RESULTS

Among 199 participants enrolled at baseline, 156 (78.4%) were retained at both 3 and 6 months. Baseline characteristics [18] did not differ significantly between participants who were and were not retained at follow-up. Participants were mostly male in their mid-30s and had been injecting drugs for a mean of 16.6 years (SD = 8.6). At 3 months, 43.3% reported recent high-risk injecting (receptive syringe sharing, using pre-filled syringe, back- or front-loading or container sharing). About a third (29.3%) reported considering themselves at risk of acquiring HIV via injection, while 5.1% perceived being at risk through sexual intercourse. One participant tested positive for HIV at 3 months and none at 6 months [18].

Figure 1 shows the cross-tabulation of observed TFVdp/FTCtp concentrations at 3 and 6 months. At both visits, most participants had unquantifiable levels of both metabolites (65.0% at 3 months and 72.2% at 6 months) consistent with less than 1 dose/week PrEP intake during the previous 2 months. A small proportion had TFVdp/FTCtp concentrations consistent with regular dosing of ≥ 4 doses/week (1.3% at 3 months and 3.2% at 6 months).

Figure 2 illustrates the longitudinal dynamics of PrEP intake and suggests that adherence worsened over time: 21.8% demonstrated worsened and 13.5% improved adherence at 6 months compared to 3 months. While 7.1% had TFVdp/FTCtp levels consistent with regular intake of ≥ 2 doses/week, only 1.3% were regularly taking ≥ 4 doses/week. Over half (53.8%) had no detectable metabolites at both assessments. Clustering of observations in cells B/C/F suggests that “white coat compliance”—a phenomenon when patients exhibit improved adherence before the clinic visit [27]—was prevalent in our study.

The results of multinomial logistic regression (Table 1) show that both worsened and improved adherence were associated with longer drug injection duration and recent alcohol use compared to consistent non-adherence. Worsened adherence was also associated with younger age and absence of overdose. Consistent adherence (≥ 2 doses/week) was associated with the study intervention (SMS reminders), younger age, employment, lower income, longer injecting drug use duration, recent high-risk injecting, absence of overdose, perceived HIV risk through sexual intercourse and

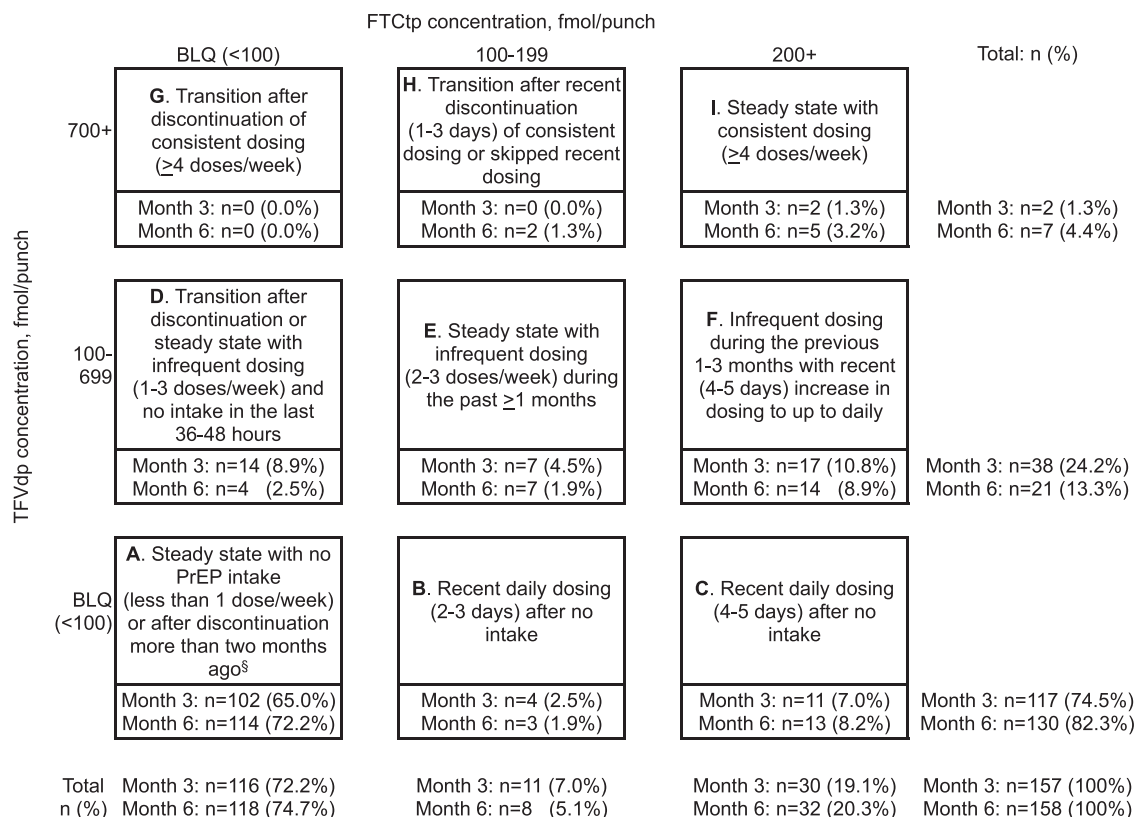


Figure 1. Observed combinations of TDF/FTC metabolite levels in dried blood spot and their possible interpretations among people who inject drugs in Kyiv, Ukraine during July 2020–March 2021. Cell labels represent pharmacokinetic interpretations of metabolite combinations in the study population and do not capture all possible variation of dosing scenarios. Abbreviations: BLQ, below the limit of quantification; FTC, emtricitabine; FTCtp, emtricitabine triphosphate; TFV, tenofovir; TFVdp, tenofovir diphosphate. ^sRecent PrEP intake of a single dose less than 2–8 hours before the blood draw or 3–7 days before the blood draw in the absence of regular intake would result in the FTCtp concentration that falls below the limit of quantification; however, long-term steady state dosing of 1 dose/week is consistent with TFVdp concentration of about 300 fmol/punch, which falls above the limit of quantification for TFVdp.

higher self-efficacy of PrEP adherence. The analysis of correlates of improved versus worsened adherence found no associations with any of the candidate covariates (data not shown).

4 | DISCUSSION

To the best of our knowledge, this is the first study that investigated PrEP adherence dynamics among PWID leveraging distinct pharmacokinetic profiles of two PrEP metabolites. The parent study [18] was designed to model a real-life community-based PrEP programme: participants received PrEP for take-home dosing, no incentives were offered for intake, and counselling and information were provided in accordance with the national protocols; participants were not penalized for low adherence.

We found that overall PrEP compliance was low and worsened as time progressed, with only 7.1% of participants showing evidence of consistent intake of ≥ 2 doses/week, and 1.3% taking ≥ 4 doses/week. “White coat compliance” [27] observed in our study suggests that in a real-life community-based PrEP

programme without regular clinical encounters and continued support, adherence may be even lower. This emphasizes that while PrEP offers the potential in reducing HIV transmission among PWID, it may not produce the expected effect in isolation and must be viewed as a component of a comprehensive patient-centred harm-reduction package designed to address individual and structural barriers [28]. PrEP should be available, accessible and offered freely to those who would like it, paired with frequent HIV testing to ensure that people who seroconvert are detected early and switched to a full antiretroviral regimen in a timely manner [29, 30]. Behavioural and pharmaceutical HIV prevention interventions with proven effectiveness, including needle/syringe programmes, medications for opioid use disorder and ongoing psychosocial support, remain critical in sustaining risk reduction in Ukraine and the eastern Europe and central Asia (EECA) region, where HIV epidemics continue to be driven by unsafe drug injection [19, 28, 31].

The parent study analysis found no significant effect of the trial intervention (SMS reminders) on PrEP adherence [18]. However, analysis of adherence patterns presented in this paper shows that consistent adherence was associated

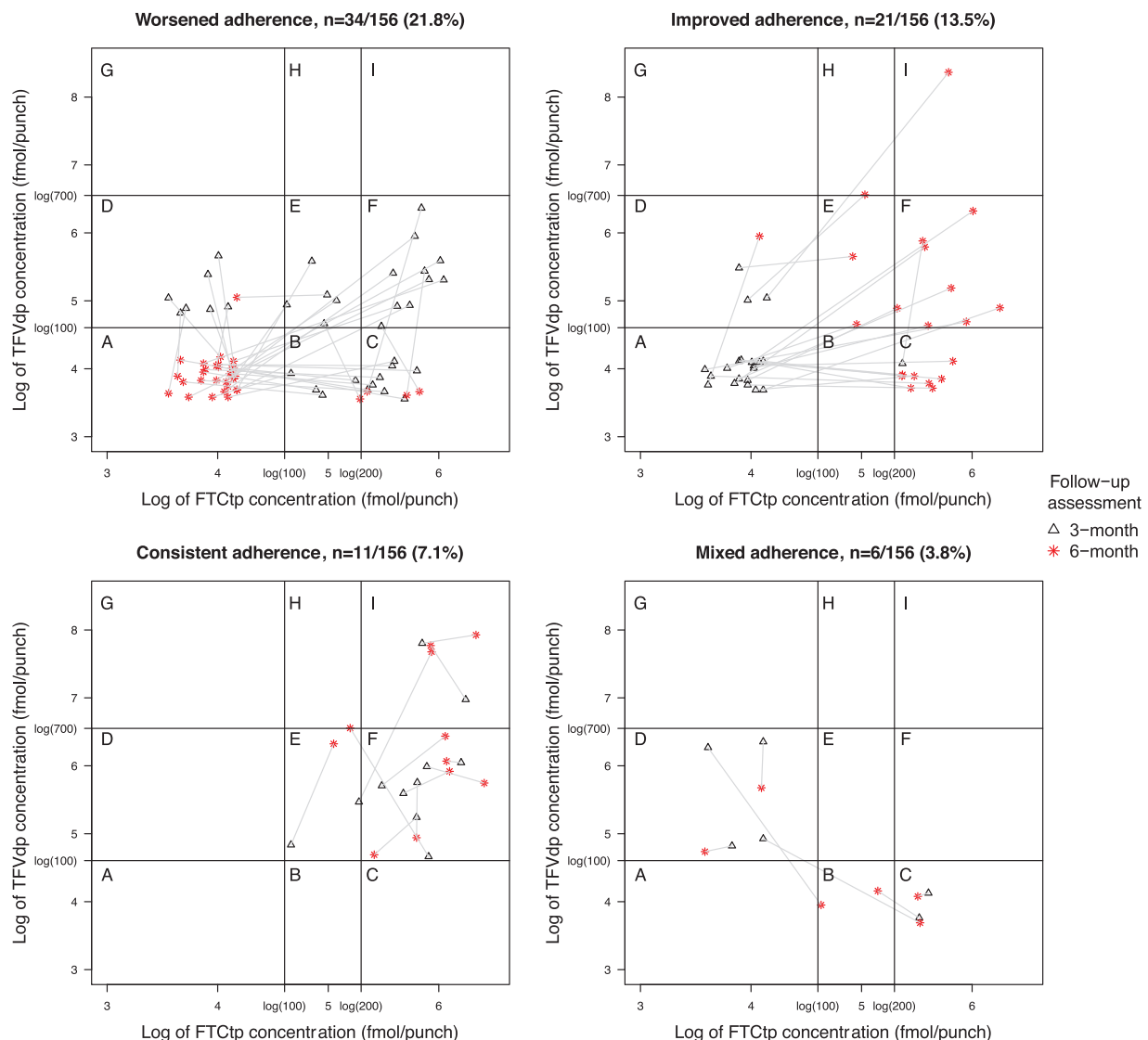


Figure 2. Dynamics of TDF/FTC metabolite levels in dried blood spot between 3- and 6-month assessments in the groups of participants with worsened ($n = 34$), improved ($n = 21$), consistent ($n = 11$) and mixed ($n = 6$) daily oral PrEP adherence among people who inject drugs in Kyiv, Ukraine during July 2020–March 2021. Each study participant is represented by a black triangle showing TFVdp/FTCtp concentrations at 3-month assessment, a red star showing TFVdp/FTCtp concentrations at 6-month assessment and a grey line connecting the two symbols to show changes in TFVdp/FTCtp concentrations for each individual. Plotting cells labelled A–I correspond to TDF/FTC metabolite concentration thresholds described in Figure 1. For illustration purposes, TFVdp/FTCtp concentrations below quantification limit (100 fmol/punch for either metabolite) were imputed using random number generator (values between 35 and 65). Metabolite concentrations are plotted on a log scale. Abbreviations: FTC, emtricitabine; FTCtp, emtricitabine triphosphate; TFV, tenofovir; TFVdp, tenofovir diphosphate.

with SMS reminders compared to non-adherence. Failure to detect the overall effect was, therefore, likely driven by the small proportion of participants who benefited from the intervention, diluting the effect size in the overall sample. In the adherent group, text messages likely served as a reminder to take a pill, while producing little to no effect among participants who may not have seen PrEP as a priority.

The parent study results suggest that self-reported motivation and adherence may not serve as reliable predictors

of PrEP intake [18]. Despite the small sample size, in the present analysis, we found many factors associated with consistent adherence that may provide practical guidance in identifying groups that are likely to benefit from PrEP and those who require additional support. One encouraging finding was that consistent PrEP adherence was associated with recent high-risk injection and perceived HIV risk via sexual intercourse, suggesting that people at higher risk of HIV acquisition were more likely to adhere to PrEP. Association between PrEP intake and longer drug use history may further support

Table 1. Multinomial logistic regression: correlates of worsened, improved and consistent PrEP adherence at ≥ 2 doses/week compared to consistent lack of PrEP intake among PWID in Kyiv, Ukraine during July 2020–March 2021 (N = 150)

Characteristic	Worsened adherence (n = 34)			Improved adherence (n = 21)			Consistent adherence (n = 11)		
	beta	p-value	aOR (95% CI)	beta	p-value	aOR (95% CI)	beta	p-value	aOR (95% CI)
Study arm									
no SMS	ref			ref			ref		
SMS	0.25	0.5883	1.29 (0.52–3.21)	0.06	0.9098	1.06 (0.36–3.12)	2.47	0.0443	11.81 (1.07–>100)
Age (years)	-0.15	0.0145	0.86 (0.76–0.97)	-0.03	0.6176	0.97 (0.85–1.10)	-0.35	0.0059	0.71 (0.55–0.91)
Sex									
female	ref			ref			ref		
male	-0.46	0.4183	0.63 (0.21–1.92)	-0.84	0.2089	0.43 (0.12–1.60)	-0.48	0.6824	0.62 (0.06–6.11)
Marital status									
partner	ref			ref			ref		
single	-0.10	0.8447	0.91 (0.34–2.40)	-0.31	0.6206	0.74 (0.22–2.48)	-1.93	0.1083	0.14 (0.01–1.53)
Employment									
employed (full or part)	ref			ref			ref		
unemployed	0.12	0.8466	1.13 (0.34–3.77)	-0.43	0.5932	0.65 (0.14–3.12)	-4.61	0.0331	0.01 (<0.01–0.69)
Income (UAH per month)									
≤ 3000	ref			ref			ref		
3001–8000	-0.79	0.2097	0.45 (0.13–1.56)	-0.92	0.2539	0.40 (0.08–1.93)	-2.42	0.0669	0.09 (0.01–1.18)
>8000	-1.16	0.0934	0.31 (0.08–1.22)	-0.82	0.3061	0.44 (0.09–2.13)	-4.35	0.0037	0.01 (<0.01–0.24)
Duration of injection drug use (lifetime, years)	0.15	0.0070	1.16 (1.04–1.29)	0.13	0.0302	1.14 (1.01–1.28)	0.27	0.0262	1.30 (1.03–1.65)
Alcohol use in the past 30 days									
no	ref			ref			ref		
yes	1.29	0.0161	3.64 (1.27–10.41)	1.41	0.0355	4.10 (1.10–15.30)	0.67	0.5560	1.96 (0.21–18.56)
High-risk injecting in the past 30 days ^a									
no	ref			ref			ref		
yes	0.91	0.0748	2.48 (0.91–6.73)	1.02	0.0920	2.76 (0.85–9.01)	4.43	0.0045	83.75 (3.94–>100)
Overdose in the last 6 months									
no	ref			ref			ref		
yes	-15.35	<0.0001	<0.01 (<0.01)	-0.91	0.3665	0.40 (0.06–2.90)	-26.75	<0.0001	<0.01 (<0.01)
MOUD at present									
no	ref			ref			ref		
yes	-0.18	0.7264	0.83 (0.30–2.31)	0.50	0.3909	1.65 (0.52–5.21)	-1.27	0.2799	0.28 (0.03–2.81)
Depression (PHQ-9)									
none or mild	ref			ref			ref		
moderate to severe	-0.11	0.8225	0.90 (0.35–2.32)	0.35	0.5431	1.42 (0.46–4.41)	1.40	0.1914	4.06 (0.50–33.24)

(Continued)

Table 1. (Continued)

Characteristic	Worsened adherence (n = 34)			Improved adherence (n = 21)			Consistent adherence (n = 11)		
	beta	p-value	aOR (95% CI)	beta	p-value	aOR (95% CI)	beta	p-value	aOR (95% CI)
Perceived HIV risk through injection									
no	ref			ref			ref		
yes	0.05	0.9263	1.05 (0.37–2.94)	–0.45	0.4846	0.64 (0.18–2.23)	–0.96	0.3651	0.38 (0.05–3.06)
Perceived HIV risk through sexual intercourse									
no	ref			ref			ref		
yes	2.50	0.0936	12.16 (0.66–>100)	1.88	0.2306	6.55 (0.30–>100)	8.76	0.0008	>100 (38.83–>100)
Self-efficacy of adherence to daily PrEP last month									
poor to moderate	ref			ref			ref		
good to excellent	0.43	0.6401	1.54 (0.25–9.35)	0.02	0.9809	1.02 (0.16–6.48)	15.94	<0.0001	>100 (>100)

Note: In the multinomial regression, the reference group was participants with consistent lack of PrEP adherence across 3- and 6-month assessments (N = 84). All time-varying covariates were measured at 3-month assessment visit. Odds ratios lower than 0.01 are reported as “<0.01” and odds ratios higher than 100 are reported as “>100.” Associations significant at 0.05 level are bolded. There were no missing values on individual variables due to survey implementation via computer-assisted instruments.

Abbreviations: aOR, adjusted odds ratio; CI, confidence interval; MUD, medications for opioid use disorder; PHQ-9, patient health questionnaire, 9-item version; PrEP, pre-exposure prophylaxis; PWID, people who inject drugs; SMS, short messages service; UAH, Ukrainian hryvnia (Ukraine national currency).

^aHigh-risk injecting includes self-report of any of the following: receptive syringe sharing, using pre-filled syringe, back- or front-loading or container sharing.

this, as HIV may be more prevalent in networks of PWID who have used injection drugs for longer and may also have better awareness of associated risks. Perceived risk of HIV acquisition via drug injection, while more prevalent, was not associated with PrEP adherence. This may suggest that PrEP intake led to the feeling of protection and thus lower perceived risk or that high-risk injection practices may not translate into risk perception [32], possibly due to higher risk tolerance towards more familiar practices.

We found that groups with improved and worsened adherence were similar with respect to all covariates suggesting that these people may be taking PrEP periodically rather than representing distinct subgroups who gain or lose interest in PrEP over time, but a larger sample size is needed to confirm this hypothesis. Of note, alcohol use was associated with both improved and worsened adherence, but not with consistent adherence, suggesting that alcohol use—a known risk factor for HIV acquisition [33]—may be related to unstable behaviours, in particular with respect to sexual HIV transmission [34], resulting in periodic PrEP intake.

Our study had several limitations. Despite being the largest study to date to analyse PrEP biomarkers among PWID, insufficient heterogeneity in outcomes resulted in small samples in some groups and consequently wide confidence intervals around regression coefficients. Only two participants were consistently taking ≥ 4 doses/week (dosing level shown to offer sufficient protection [9]), prohibiting the analysis of correlates of this outcome. While the study implementation overlapped with the COVID-19 pandemic, evidence suggests that the impact of the pandemic on the local drug scene, harm reduction and clinical services for PWID was short-term [35, 36] and unlikely to meaningfully affect our results.

In the past two decades, Ukraine achieved considerable progress in curbing the HIV epidemic [22, 37–39]. The ongoing war with Russia disrupted lives and put pressure on governmental and community systems that provided supporting structures to the most vulnerable [40–43]. At the same time, Ukrainian society demonstrated strong resilience in the face of the crisis. Critical HIV services continue to be delivered on the territories controlled by Ukraine with a central role played by the communities of people living with HIV and people who use drugs [44–46]. Confronted with the risk of surging transmission, it is vital to leverage all available tools, including PrEP, to reduce the spread of HIV among key populations. Findings from our study suggest that in the current Ukrainian context, comprehensive integrated harm reduction strategies are more important than ever to improve the efficacy of HIV prevention through synergies.

5 | CONCLUSIONS

While long-acting injectable PrEP shows promise in improving adherence [30, 47–49], its efficacy has not been tested among PWID, and daily oral PrEP remains the only option currently available to this group. Without proper integration with effective risk reduction strategies and addressing structural barriers to care engagement, PrEP may be unable to achieve the effects demonstrated in clinical trials. It is especially important in the context of HIV epidemics associated with injection drug

use in the EECA region and the public health crisis in Ukraine caused by the war with Russia. As adherence may worsen over time, the findings from our study offer practical guidance in identifying groups of PWID who may benefit from additional support to improve PrEP compliance. While the effect of SMS reminders was small, the intervention may be beneficial to some people. Further research involving biomarkers is needed to investigate reasons for low compliance and test interventions that may lead to better outcomes, including case management, peer navigation, cash incentives, and determining the efficacy and the implementation modalities of long-acting injectable PrEP among PWID.

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COMPETING INTERESTS

The authors report no competing interests.

AUTHORS' CONTRIBUTIONS

OM: Conceptualization, methodology, formal analysis, supervision, validation, writing—original draft, writing—review and editing. MK: Conceptualization, funding acquisition, investigation, writing—review and editing. OM: Project administration, writing—review and editing. SA: Methodology, writing—review and editing. ML: Resources, writing—review and editing. OV: Funding acquisition, supervision, investigation, writing—review and editing. KD: Methodology, supervision, writing—review and editing.

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DISCLAIMER

The content of this publication is solely the responsibility of the authors and does not necessarily represent the official views of the funders.

DATA AVAILABILITY STATEMENT

According to the data-sharing policy of the Alliance for Public Health, the data obtained from this study cannot be made publicly available due to privacy or ethical restrictions. However, it can be provided upon a reasonable request, which should be directed to office@aph.org.ua.

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RESEARCH ARTICLE

Being yourself is a defect: analysis of documented rights violations related to sexual orientation, gender identity and HIV in 2022 using the REAct system in six eastern European, Caucasus and Central Asian countries

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Abstract

Introduction: Removing legal barriers to HIV services is crucial for the global 2030 goal of ending the HIV and AIDS epidemic, particularly in eastern Europe, the Caucasus and central Asia. Despite state commitments to uphold human rights, gay, bisexual and other men who have sex with men (gbMSM), along with transgender people (TP) still face stigma and discrimination. This article presents an analysis of rights violations based on sexual orientation and gender identity (SOGI) and HIV reported in 2022 across six countries, highlighting features and their links to legislation and law enforcement practices.

Methods: We examined documented cases of rights violations among gbMSM and TP in Armenia, Kazakhstan, Kyrgyzstan, Tajikistan, Uzbekistan and Ukraine in 2022 using the REAct system, a tool for documenting and responding to rights violations against key populations. Initially, we employed directed content analysis based on Yogyakarta Principles to analyse narratives of violations. A codebook was developed through contextual, manifest and latent coding, with themes, categories and codes converted into quantitative variables for statistical analysis. Descriptive statistics were used to identify the characteristics of violations.

Results: A total of 456 cases of rights violations related to SOGI and HIV were documented, ranging from 22 cases in Tajikistan to 217 in Ukraine. Most violations concerned gbMSM (76.5%), with one-fifth involving TP, predominantly transgender women. Complex violations with multiple perpetrators or infringements were documented in Armenia and central Asia. Privacy rights were commonly violated, often through outing. Cases of violations of the right to the highest attainable standard of health (13.6%) and protection from medical abuses (2.6%) were also documented. Other rights violations were sporadic, with each country exhibiting distinct patterns of violated rights and types of violations. In Ukraine, the full-scale war in 2022 influenced the nature of documented cases, reflecting the challenges faced by gbMSM and TP.

Conclusions: Monitoring rights violations proved effective for assessing the situation of gbMSM and TP, particularly in the insufficiently studied and diverse eastern Europe, Caucasus and central Asia regions. As rights violations are linked to both legislation and law enforcement practices, comprehensive interventions to minimize structural and interpersonal stigma are essential.

Keywords: human rights; men who have sex with men; transgender people; eastern Europe; Caucasus and central Asia; sexual orientation and gender identity

Additional information may be found under the Supporting Information tab of this article.

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1 | INTRODUCTION

Eliminating legal barriers to HIV services is crucial for achieving the global goal of ending the HIV and AIDS epidemic by 2030 [1, 2], particularly among gay, bisexual and other men who have sex with men (gbMSM) and transgender people

(TP, including transgender men and transgender women) in eastern Europe, Caucasus and central Asia (EECCA). UNAIDS data indicate a rapid 49% increase in new HIV cases in the region from 2010 to 2022 [3], with gbMSM and TP accounting for 22.0% and 0.8%, respectively, among the 160,000 people who newly acquired HIV [4]. The median HIV prevalence

was 4.3% among gbMSM and 1.7% among TP [3]; however, data for the EECCA region are limited [5–7].

Despite states' commitments to uphold the rights of gbMSM and TP [8] and contribute to the Sustainable Development Goals [9], community representatives continue to face stigma and discrimination. Studies partially indicate a direct link between rights violations and HIV seropositivity among gbMSM and TP [10, 11]. Structural stigma, marked by the absence of protective policies, and interpersonal and individualized stigma, along with direct experience of rights violations, lead to risky behaviours like unprotected sex and drug use [12–14]. Stigma complicates access to medical, social and legal services [15, 16], reducing readiness for HIV prevention [17] and testing [11, 18]. Intersectional identities (intersectionality [19]) exacerbate stigmatization and discrimination, particularly for gbMSM and TP involved in sex work or living with HIV [20, 21], highlighting the complexity of challenges faced by these populations. In countries of the former Soviet Union, gbMSM and TP rights protection remains inadequate [22], leading to ongoing rights violations [23]. International indices highlight a high prevalence of homophobia and transphobia [24, 25], although variations exist within the region [23–27]. For example, Uzbekistan and Turkmenistan still criminalize consensual same-sex relations between men.

Efforts to eliminate stigma and discrimination based on sexual orientation and gender identity (SOGI), alongside gender-equitable HIV programmes, effectively restrain HIV spread [8, 28]. Rights monitoring by non-governmental organizations (NGOs) and community-based organizations enhances protection [29] and is vital for developing democratic, evidence-based policies [30] and improving HIV programme design and effectiveness [31].

In this article, we present the results of the analysis of documented rights violations among gbMSM and TP across six EECCA countries in 2022, highlighting the specific patterns and the impact of laws and enforcement. As rights violations among key populations (KPs) in the region are understudied, our findings contribute valuable evidence crucial for eliminating legal barriers and advocating for the health rights of the gbMSM and TP.

2 | METHODS

2.1 | REAct overview

Developed by Frontline AIDS, the “Rights—Evidence—Action” (REAct) is a community-based tool to monitor and respond to human rights violations [32]. Implemented in Ukraine by the International Charitable Foundation “Alliance for Public Health” (APH) since 2019, and funded by the Global Fund to Fight AIDS, Tuberculosis and Malaria, it was adopted by 63 NGOs in 18 Ukrainian regions by 2022. In 2022, the Eurasian Coalition on Health, Rights, Gender and Sexual Diversity (ECOM) expanded REAct to Armenia, Kazakhstan, Kyrgyzstan, Tajikistan and Uzbekistan, focusing on gbMSM and TP rights violations [33].

REAct enables KPs to report violations to a case documenter (“REActor”) in person or online [34], promoted by community activists through NGOs and social media. Regional teams, including KPs and NGOs staff, register cases upon

receiving complaints. REAct criteria require cases to be individual-specific (in Ukraine), involve actual rights violation, be reported by survivors or close associates, relate to the survivor's HIV status or KP and be distinct from previously documented incidents. Non-violations include routine help requests or unrelated scenarios to HIV status or SOGI. REActors document each case through an interview, detailing the violation's location, timing, perpetrators and witnesses, reasons, and nature, aligning with recommended guidelines [35, 36]. Following the interview, REActors develop action plans, offer consultations, psychological support and refer the survivor to legal or specialized services, while monitoring each case and logging them into an information system.

All REAct operations follow standardized guidelines and tools from Frontline AIDS [32], ensuring regional consistency and tool adaptation to local languages and data collection needs, enhancing documentation effectiveness and reliability.

2.2 | Population and setting

In February 2023, we conducted a secondary data analysis of gbMSM and TP (transgender men and transgender women) rights violation cases documented in the REAct system across six countries in 2022: Armenia (Caucasus), Kazakhstan, Kyrgyzstan, Tajikistan, Uzbekistan (central Asia) and Ukraine (eastern Europe). Data on the legal and social dimensions of gbMSM and TP rights and the HIV landscape in these countries are annually compiled by ECOM [23, 37–39].

Our analysis used a dataset provided by REAct coordinators in Ukraine (APH) and the remaining five countries (ECOM), ensuring no personalized information about survivors, only descriptions of gbMSM and TP right violation cases. Coordinators reviewed case descriptions to guarantee adherence to ethical standards and criteria before handing them to the research team. All cases were checked for discrimination based on SOGI or HIV, and no duplicates were found.

The analysis included cases of rights violations against survivors self-identifying as gbMSM, TP and lesbian, bisexual and queer women, as well as community-wide violations (without specifying individual SOGI) like hate speech from media, political or religious figures. Additionally, cases involving people living with HIV who identify as gbMSM or TP and face rights violations related to their HIV status were included.

2.3 | Data processing and analysis

To convert qualitative data into quantitative, a direct content analysis approach [40] was used, with the Yogyakarta Principles on the application of international human rights law in relation to SOGI [41] as a foundational framework to categorize human rights and potential violations related to gbMSM and TP issues. The themes, categories and codes identified formed the basis for a preliminary codebook.

Each case description was analysed to identify key elements indicating specific human rights violations and characteristics of the violation, such as the type of perpetrator. Contextual coding [42] helped understand the cultural context of each case [43]. Manifest coding was used to identify explicit

mentions of violations, while latent coding helped detect sub-
letter indicators [44, 45].

During the coding stage, the codebook was updated for accuracy and completeness. Initially, one researcher (OK) created a preliminary codebook. For reliability, three researchers (OK, ET and NM) independently coded 10% of cases. After primary coding, discrepancies were resolved through consensus discussion. The remaining cases were coded by two researchers (OK and ET), with ongoing codebook refinement. The final codebook, reviewed and approved by NM, is presented in [File S1](#).

Themes, categories and codes were converted into quantitative variables for statistical analysis. For example, if torture was identified, the corresponding variable was assigned as “1”; otherwise, it was assigned a “0.” Descriptive statistics included variables such as survivors’ SOGI, involvement of minors, violation basis, number and type of perpetrators, and violation type. One case could involve multiple perpetrators, violation types and violated rights. Instances of name-calling and verbal abuse related to SOGI or HIV were not classified separately, as they were common in documented cases and were included in the variable “Hate speech and public incitement by individuals” if the case was limited to that aspect.

Data processing and analysis were performed using Microsoft Excel and IBM SPSS Statistics 28.0 (IBM SPSS Statistics for Windows, Version 28.0. Armonk, NY: IBM Corp).

2.4 | Ethical considerations

During violation reporting and response, principles of privacy, confidentiality and voluntary participation were maintained. REActors were trained in methodologies, human rights, legislation and providing appropriate support to minimize re-traumatization risks. Private communication with survivors included thorough threat and risk assessment to address potential issues such as family retaliation or punitive laws against homosexual relationships, with mitigation strategies aligned with international protocols [46]. Paper documentation was destroyed post-entry for confidentiality, and a security plan [47] was implemented for data protection.

Survivors reporting rights violations through REAct were asked to provide three separate written informed consents tailored to each purpose: (1) to document the case and participate in the interview; (2) to use the de-personalized case description for advocacy and research; and (3) to use personal data for legal submission if they chose to involve a lawyer. If a survivor declined certain consents, they still received appropriate services according to their agreed participation level. For example, if a survivor declined advocacy and research consent but agreed to data sharing with a lawyer, they received legal assistance without their case being used for advocacy or analysis. If a survivor consented only to project participation, their case was used solely for programme monitoring by the REAct coordinator, including counting documented cases, assessing assistance effectiveness, and determining resolution and resource use. Informed consent forms [48] were developed by Frontline AIDS [32] and adapted for each country.

In this study, we analysed textual descriptions of rights violations collected by the REAct system, initially designed

for reporting and responding to such violations. The analysis, limited to narrative descriptions without identifiable information, was determined not to involve human subjects research, and a full ethical review was waived (Institutional Review Board No. 1 of the charity organization “Ukrainian Institute on Public Health Policy,” IRB#00007612, FWA #00029648). All cases included were verified by REAct coordinators from APH and ECOM to ensure survivor consent for research use and the absence of confidential information. No refusals were recorded; thus, all documented cases reported for 2022 from each country were included in the analysis.

3 | RESULTS

In 2022, a total of 456 gbMSM and TP rights violation cases were documented across six countries: 217 in Ukraine, 80 in Armenia, 79 in Uzbekistan, 32 in Kyrgyzstan, 26 in Kazakhstan and 22 in Tajikistan (Table 1). Most survivors were gbMSM (76.5%), while TP constituted 20%, primarily transgender women. Nearly, all cases (98.5%) involved SOGI-based violations, sometimes intersecting with HIV status. Kyrgyzstan (43.8%) and Kazakhstan (26.9%) reported higher proportions of HIV-related cases.

Almost half of the cases included multiple rights violations (33.6% in Ukraine to 77.3% in Tajikistan), with 60.3% involved multiple types of violations. Group perpetrators were involved in 46.9% of cases, notably in Uzbekistan (60.8%) and Tajikistan (68.2%). Deceptive dating (where a non-gbMSM or TP person connects via social media for a date to exploit and manipulate information about counterpart’s SOGI) mostly seen in Uzbekistan (40.5%) compared to 12.9% overall.

Perpetrators were commonly unidentified (25.7%) or law enforcement officers (20.0%), with the latter being particularly prominent in Tajikistan (63.6%). In Armenia, violations by clients of sex workers (SWs) were substantial (8.8%), while Kazakhstan and Kyrgyzstan reported more violations by healthcare facilities. Military involvement in violations was noted in Tajikistan (13.6%) and Ukraine (11.5%). Ukraine and Tajikistan had no cases involving clients of SWs, religious leaders or media representatives as perpetrators, unlike other countries. In Ukraine, colleagues/classmates and acquaintances were significant perpetrators, as were service industry workers (9.2%) compared to 4.8% across other countries.

The analysis of gbMSM and TP rights violations in REAct across six countries revealed disparities in the nature and frequency of these violations (Table 2). Among these, 38.2% involved infringements of the right to privacy, primarily through outing, while 35.3% were linked to the right to personal security. Physical violence, the most prevalent form of personal security violation, ranged from 11.5% in Kazakhstan to 30.4% in Uzbekistan. Uzbekistan notably had a third of the cases involving property damage and material harm related to the right to recognition before the law. Ukraine had cases related to denial of services due to transgender transition, accounting for 2.3% of all cases. Torture by law enforcement was documented in 36.4% of cases in Tajikistan, higher than the overall average of 4.8%.

Table 1. Rights violation cases by countries, 2022

Characteristic	AM %	Central Asia				UA %	Overall %
		KZ %	KG %	TJ %	UZ %		
Total cases (N)	80	26	32	22	79	217	456
SOGI of survivor							
MSM, gay and bisexual men	52.5	61.5	93.8	63.6	87.3	82.0	76.5
Transgender men	3.7	–	6.2	–	–	6.0	4.0
Transgender women	37.5	23.1	–	36.4	3.8	12.0	16.0
Lesbian, bisexual and queer women	3.8	–	–	–	1.3	–	0.9
Entire LGBT community (without specific SOGI)	2.5	15.4	–	–	7.6	–	2.6
Cases involving minors	6.3	–	3.1	–	1.3	0.5	1.8
Basis of violation							
SOGI	100.0	84.6	93.8	100.0	100.0	99.5	98.5
HIV	3.8	26.9	43.8	9.1	6.3	3.2	8.3
SW	8 10.0	11.5	6.3	13.6	6.3	–	4.6
Combined basis of violation							
SOGI only	86.3	61.5	50.0	77.3	87.3	96.8	87.1
SOGI and HIV	3.8	11.5	37.5	9.1	6.3	2.8	6.8
SOGI and SW	10.0	11.5	6.3	13.6	6.3	–	4.6
HIV only	–	15.4	6.3	–	–	0.5	1.5
Cases with multiple violated rights	45.0	42.3	43.8	77.3	72.2	33.6	45.6
Cases with multiple types of violations	60.0	53.8	78.1	86.4	84.8	47.0	60.3
Cases involving group perpetrators	47.5	50.0	40.6	68.2	60.8	40.1	46.9
Cases with multiple types of perpetrators	26.3	19.2	15.6	22.7	19.0	8.3	15.1
Type of perpetrators							
Unidentified person	30.0	26.9	15.6	13.6	34.2	23.5	25.7
Police	18.8	15.4	25.0	63.6	31.6	11.5	20.0
General healthcare facility	17.5	–	28.1	4.5	2.5	8.8	9.9
Relative	13.8	7.7	6.3	4.5	15.2	6.5	9.2
Military	–	–	–	13.6	–	11.5	7.7
Employer	2.5	11.5	12.5	–	3.8	7.4	6.1
Colleague, classmate	3.8	–	6.3	–	2.5	7.4	5.0
Service industry worker	2.5	–	–	–	–	9.2	4.8
Neighbour	1.3	–	–	–	7.6	5.5	4.2
Sexual partner	2.5	–	–	9.1	8.9	3.7	4.2
HIV/AIDS healthcare facility	2.5	15.4	6.3	4.5	2.5	1.8	3.3
Government official	3.8	7.7	3.1	4.5	–	3.2	3.1
SW' client	8.8	11.5	6.3	–	1.3	–	2.9
Landlord	–	7.7	–	4.5	–	4.1	2.6
Media, blogger	6.3	7.7	3.1	–	3.8	–	2.4
Educational institution	1.3	3.8	3.1	–	1.3	0.9	1.3
Acquaintance	1.3	–	–	–	1.3	1.8	1.3
Religious leader	1.3	3.8	3.1	–	2.5	–	1.1
State lawyer	–	–	–	–	3.8	0.5	0.9
Non-governmental organization	–	3.8	–	–	1.3	0.5	0.7
Cases involving deceptive dating	2.5	23.1	18.8	9.1	40.5	5.1	12.9

Abbreviations: AIDS, acquired immunodeficiency syndrome; AM, Armenia; HIV, human immunodeficiency virus; KG, Kyrgyzstan; KZ, Kazakhstan; LGBT, lesbian, gay, bisexual and transgender people; MSM, men who have sex with men; SOGI, sexual orientation and gender identity; SW, sex work; TJ, Tajikistan; UA, Ukraine; UZ, Uzbekistan.

Table 2. Types of rights violations based on SOGI and HIV by countries, 2022

Right/violation type	AM %	Central Asia				UA %	Overall %
		KZ %	KG %	TJ %	UZ %		
Privacy	31.3	38.5	43.8	54.5	74.7	24.9	38.2
Disclosure or threat of disclosing SOGI (outing)	22.5	19.2	28.1	23.7	54.4	19.4	27.0
Extortion of money	5.0	19.2	18.8	31.8	31.6	6.5	13.4
Unauthorized access to private correspondence	2.5	7.7	9.4	18.2	15.2	6.9	8.3
Unauthorized home or personal inspection	1.3	—	—	4.5	2.5	3.7	2.6
Coercion to disclose partner information	2.5	3.8	9.4	13.6	3.8	—	2.6
Disclosure or threat of disclosing HIV status	1.3	3.8	6.3	—	2.5	0.9	1.8
Criminalization of MSM	—	—	—	—	7.6	—	1.3
Criminalization of HIV transmission	1.3	—	—	—	2.5	—	0.7
Security of the person	47.5	19.2	25.0	27.3	46.8	30.9	35.3
Physical violence	31.3	11.5	15.6	13.6	30.4	23.0	24.1
Domestic violence	11.3	7.7	3.1	9.1	15.2	6.5	8.8
Sexual violence and harassment	7.5	—	9.4	4.5	2.5	0.9	3.1
Coercion to use drugs or alcohol	1.3	—	—	—	—	0.5	0.4
Recognition before the law	15.0	11.5	6.3	22.7	31.6	13.8	16.9
Property damage and material harm	7.5	11.5	3.1	22.7	31.6	9.2	13.2
Denial to process documents related to transgender transition	5.0	—	3.1	—	—	2.8	2.4
Denial of social services based on transgender transition	—	—	—	—	—	2.3	1.1
Coercion to conceal SOGI	2.5	—	—	—	2.5	—	0.9
Freedom from torture and cruel, inhuman or degrading treatment or punishment	3.8	3.8	12.5	50.0	22.8	12.4	14.0
Other abuses of authority by security and law enforcement	3.8	3.8	9.4	13.6	17.7	12.0	11.0
Force, torture or cruelty by security and law enforcement	—	—	6.3	36.4	6.3	3.2	4.8
Highest attainable standard of health	20.0	15.4	34.4	9.1	5.1	11.5	13.6
Demeaning conduct in HCF	13.8	3.8	31.3	4.5	2.5	6.9	8.8
Denial to provide medical services	13.8	—	18.8	—	—	4.6	5.9
Disclosure of SOGI medical data	2.5	3.8	—	4.5	1.3	0.9	1.5
Disclosure of HIV medical data	—	11.5	—	4.5	1.3	—	1.1
Denial of medical services related to transgender transition	1.3	—	—	—	—	1.8	1.1
Denial to prescribe PrEP	—	—	—	—	—	1.8	0.9
Extortion of payment for medical services, whether free or paid	—	—	6.3	—	1.3	0.5	0.9
Denial of hepatitis or STI treatment	—	—	3.1	—	—	0.5	0.4
Denial to prescribe ART	1.3	—	—	—	—	—	0.2
Effective remedies and redress	12.5	15.4	3.1	9.1	8.9	5.1	7.7
Denial to provide legal assistance	12.5	15.4	3.1	9.1	8.9	5.1	7.7
Work	5.0	11.5	12.5	—	3.8	8.8	7.2
Employment termination or denial	2.5	11.5	12.5	—	3.8	5.1	5.0
Workplace bullying	3.8	—	3.1	—	1.3	5.5	3.7
Denial to pay wages	—	—	3.1	—	—	0.9	0.7
HIV certificate demand during employment	—	3.8	3.1	—	—	—	0.4
Adequate housing	2.5	—	3.1	4.5	5.1	10.1	6.6
Eviction or forced eviction	2.5	—	3.1	4.5	5.1	7.8	5.5
Denial of hotel and shelter services	—	—	—	—	—	2.3	1.1

(Continued)

Table 2. (Continued)

Right/violation type	AM %	Central Asia				UA %	Overall %
		KZ %	KG %	TJ %	UZ %		
Freedom from arbitrary deprivation of liberty	2.5	3.8	6.3	27.3	13.9	2.3	5.9
Illegal arrest or detention	2.5	—	6.3	27.3	6.3	2.3	4.4
Coercion to provide self-incriminating statements	—	3.8	—	9.1	7.6	—	2.0
Freedom of opinion and expression	6.2	15.4	6.3	—	7.6	1.8	4.6
Hate speech in media and public figures	6.3	15.4	3.1	—	6.3	0.5	3.5
Hate speech and public incitement by individuals	—	—	3.1	—	1.3	1.4	1.1
Equality and non-discrimination	2.5	—	—	—	—	6.0	3.3
Service denial or degrading conduct in the private sector	2.5	—	—	—	—	6.0	3.3
Freedom of movement	2.5	—	—	—	8.9	2.8	0.3
Forced departure from city/country	2.5	—	—	—	8.9	—	2.0
Denial to cross borders	—	—	—	—	—	2.8	1.3
Protection from medical abuses	—	11.5	3.1	9.1	5.1	0.9	2.6
Forced anal examinations	—	—	—	9.1	5.1	—	1.3
Forced HIV testing	—	7.7	3.1	—	2.5	—	1.1
Forced medical treatment	—	3.8	—	—	—	0.9	0.7
Freedom of peaceful assembly and association	1.3	11.5	—	4.5	2.5	1.8	2.4
Obstacles in the work of non-governmental organizations	—	11.5	—	4.5	2.5	1.4	2.0
Obstacles in conducting meetings	1.3	—	—	—	—	0.5	0.4
Education	1.3	—	3.1	—	—	3.2	2.0
Bullying in educational institutions	1.3	—	3.1	—	—	3.2	2.0
Life	5.0	7.7	—	—	1.3	0.5	1.8
Murder or attempted murder	5.0	7.7	—	—	1.3	0.5	1.8
Found a family	—	—	3.1	—	3.8	—	0.9
Coercion into marriage	—	—	3.1	—	3.8	—	0.9
Participate in public life	—	—	3.1	—	—	0.9	0.7
Denial of employment or dismissal from public service	—	—	3.1	—	—	0.5	0.4
Denial of employment in security and law enforcement	—	—	—	—	—	0.5	0.2
Social security and to other social protection measures	—	—	—	—	—	0.9	0.4
Denial of benefits or state assistance	—	—	—	—	—	0.9	0.4

Abbreviations: AM, Armenia; ART, antiretroviral therapy; HCF, healthcare facility; KG, Kyrgyzstan; KZ, Kazakhstan; MSM, men who have sex with men; PrEP, pre-exposure prophylaxis; SOGI, sexual orientation and gender identity; STI, sexually transmitted infection; TJ, Tajikistan; UA, Ukraine; UZ, Uzbekistan.

Violations concerning the denial of the highest attainable standard of health were most evident in Kyrgyzstan (34.4%) and Armenia (20.0%), primarily involving demeaning conduct in healthcare facilities. Ukraine documented cases of denial in prescribing pre-exposure prophylaxis (PrEP), a notable divergence from other countries. In Kazakhstan, disclosure of HIV medical data occurred in one out of every 10 cases, a proportion substantially higher than the 1.1% average across all countries. Cases of forced anal examinations were recorded in Tajikistan and Uzbekistan, and forced HIV testing was noted in Kazakhstan, Kyrgyzstan and Uzbekistan. Forced medical treatment was documented in Kazakhstan and Ukraine.

Other human rights violations of gbMSM and TP were sporadically documented. Tajikistan had a high incidence of illegal arrest (27.3%), while Kazakhstan showed a notable proportion of denial of legal assistance and restrictions on freedom of expression (15.4%), as well as obstacles in NGO functioning (11.5%). Ukraine reported cases including denial of hotel and

shelter services, forced eviction, a proportion of which were double those in other countries, employment denial in security and law enforcement, and denial of benefits or other state assistance. Ukraine's right to freedom of movement violations was primarily due to the denial of border crossing, while Uzbekistan and Armenia documented forced departures. Murders or attempted murders were recorded in several countries, totalling eight cases, while coerced marriage cases were documented in Uzbekistan and Kyrgyzstan.

4 | DISCUSSION

In this study, we analysed human rights violations related to SOGI and HIV recorded by REAct system in six EECCA countries. These findings highlight challenges faced by gbMSM and TP and provide insights for HIV programming and efforts to combat stigma, discrimination and legal barriers. The results

deepen understanding of structural and interpersonal stigma, emphasizing violations of rights based on SOGI rather than solely on HIV status [49], and revealing informal behaviour practices often overlooked in policy analyses [13].

Distinct patterns of violations across countries underscore the necessity for culturally and regionally tailored approaches. In the Caucasus and central Asia, similar to other countries with conservative social and religious norms [50], restrictions on same-sex relationships contribute to SOGI-based stigma and discrimination [5, 51], stemming from the Soviet era [52] where homosexuality was criminalized and pathologized [53]. Cases of unauthorized access to personal communication, outing, physical violence, forced departure primarily by family members and the use of hate speech illustrate this issue. Uzbekistan, where same-sex relationships have been criminalized since 1994, faces challenges aligning with studies in other countries with similar conditions [11]. Decriminalization is imperative to potentially slow the HIV epidemic and promote increased usage of healthcare services, as evidenced by comparative research on regions with and without criminalization [54]. Armenia decriminalized homosexuality and same-sex relationships in 2003, later than most regional countries, but the political environment remains unfriendly, reinforcing prejudices and exacerbating manifestations of homophobia and transphobia [55]. Transgender women in Armenia remain the most marginalized and vulnerable to violence, consistent with previously published data [56]. Nonetheless, gbMSM and TP movement has emerged in the country in recent years [57], providing avenues for expression despite lacking support from the government, politicians and media [56].

Deceptive dating, where gbMSM and TP are exploited and manipulated through deceitful online interactions, is a frequent form of exploitation also noted in other studies [58]. Perpetrators lure survivors into social network, leading to meetings that escalate into violence, illegal arrests or extortion to conceal SOGI. Perpetrators often falsely claim to be law enforcement officers to deter reporting to the police. Our findings, consistent with other studies [59], show that gbMSM and TP are affected by “revenge porn,” where explicit content is distributed without consent, leading to outing and discrimination, issues likely more prevalent than among heterosexuals [60]. In environments of high SOGI-based stigma and police indifference, online platforms become vital for community interactions and partner-seeking [11, 17], underscoring the need for awareness of safe online practices [61] and the risks of sharing personal data. Deceptive dating often targets gbMSM and TP engaged in sex work, highlighting the need for evidence-based interventions to address intersectional stigma [21].

Violations of health rights and protection from medical abuses were common, including forced anal examinations, outing and coercion to disclose of HIV status in countries with inadequate HIV legislation enforcement [54]. Epidemiological procedures in Kazakhstan [62] and Kyrgyzstan [26] led to human rights violations, emphasizing the need for enhanced healthcare provider training [50]. In Uzbekistan, health authorities must report HIV transmission to law enforcement [26], leading to partner disclosure and administrative consequences [63]. Criminalizing unintentional HIV transmission in Armenia [64] and its presence in Uzbekistan

have led to rights violations, as our findings show. Documented cases of rights violations by healthcare staff ranged from demeaning treatment to service refusal, particularly in primary healthcare settings, necessitating tolerance training and inclusive medical education.

Russia's full-scale war against Ukraine since 24 February 2022 reshaped reported rights violations in Ukraine, with reduced activity of ultra-conservative movements, rejection of locally prepared homophobic appeals, ratification of the Istanbul Convention [65], and improved attitudes towards the gbMSM and TP among Ukrainians [66]. Wartime context facilitated citizens' petitions and the inclusion of a law on civil partnership in Ukraine's Recovery Plan [23]. However, in 2022, Ukraine documented a higher proportion of housing-related violations based on SOGI, including instances of denial of temporary accommodation in hotels and shelters, within the context of dynamic internal migration resulting from the war [67]. Military-related violations increased, driven by document checks under martial law [68]. Despite this, violations commonly seen in other countries, such as unlawful arrests or physical force during detention, were less frequently documented. Border crossing challenges affected transgender women without proper certificates [69] or border guards' unfamiliarity with TP crossing procedures [70], emphasizing the need for further efforts to ensure TP rights during wartime.

In Ukraine, TP faced refusals of social services and document issuance related to their transition. Unlike the five other countries [71], Ukraine has implemented a legal procedure for transgender transition, avoiding compulsory surgeries with only an age criterion of 14 [72]. However, authorized gender marker changes based on current residence during martial law were inconsistently known by state agency personnel, resulting in violations. Anti-discrimination legislation and established transition producers in Ukraine increase service-seeking by TP [16], raising the likelihood of rights violations. Documented cases of denied PrEP prescriptions for gbMSM and TP could be linked to its popularity and availability since 2018 [73], contrasting with countries beginning PrEP implementation in 2021 [74]. Despite training programmes for medical [75] and law enforcement personnel, further development within HIV programmes is needed to minimize rights violations.

4.1 | Limitations

We acknowledge limitations in our analysis, including potential underreporting of rights violations among gbMSM and TP due to survivor's lack of awareness about REAct or choice not to report, and reliance on reports from those willing to seek help [16, 76]. Research shows high tolerance towards domestic violence among TP [77], potentially due to a lack of education and recognition of rights violation. High levels of internalized stigma reduce engagement, visibility [78, 79], awareness of services and willingness to participate in HIV prevention [80–82], thereby diminishing support for protecting their rights and participating in actions against discrimination and violence [83]. In the Caucasus and central Asia, MSM show lower self-acceptance compared to the European part of the EECCA region [83], with limited data for TP [81]. Data show higher levels of stigma and discrimination than documented,

with 36% of gbMSM in Ukraine [84] and 48% of MSM and 1% of transgender women in Yerevan, Armenia, reported feeling ashamed about their SOGI [85].

The distribution of registered cases across countries varies due to different REAct implementation periods and country-specific factors. Ukraine introduced the system in 2019, while other countries under ECOM did so in 2022, leading to varying effectiveness levels based on monitoring team experience and capability. Ukraine's sustained initiatives highlight the system's values, as REAct recorded 108 violations against gbMSM in 12 regions in its first year [86], increasing to 217 by 2022. The number of documented cases can be partly explained by its more supportive legal environmental and reduced structural barriers [79], as Ukraine has the highest level of legal protection for these communities [23]. Reduced structural stigma encourages more active participation of gbMSM and TP in research [5, 10], engagement with NGOs [14], contrasting with Tajikistan's legislative restrictions on community-based NGOs registration [23], potentially leading to fewer reported violations and increased HIV transmission risk as found in a recent African study [54]. Comparing estimated numbers of gbMSM and TP reveals disparities across countries, making direct comparisons of cases based on absolute numbers unreliable. Ukraine reported the highest number of cases, with 152,267 gbMSM [87], while other countries varied from 3000 to 62,000 [37]. In Ukraine, the estimated number of TP stands at 9963 people [87], while in Armenia and Kyrgyzstan, it does not exceed 1000 TP [38].

Differences in implementing REAct system between the Caucasus and central Asia region and Ukraine have contributed to diverse survivor profiles. ECOM focused on gbMSM and TP rights, while other organizations documented violations against other KPs [34]. The Ukrainian project included all KPs, addressing gbMSM and TP among others. A recent study found that 28.6% of male and transgender SWs faced violence, with only 7.9% seeking help [88], and violations against gbMSM and TP in sex work might have been documented as SWs' violations, contributing to a lower sexual abuse rate. Unlike the CCA countries, Ukraine lacked documented violations against the entire LGBT community, possibly due to criteria for documenting violations. Data likely underrepresent lesbian, bisexual and queer women, as they are not recognized as KP [27, 89–92], but analysed cases show their rights violations and vulnerability to HIV acquisition [93].

While Ukraine records the highest number of violations, the REAct's coverage may be incomplete due to expanding rights documentation projects [65, 94, 95]. Independent programmes plan a coordinated effort in 2024 to overcome legal barriers affecting KPs [96, 97], promising more comprehensive data.

5 | CONCLUSIONS

Our study in six EECCA countries provides crucial insights into the rights violations among gbMSM and TP in 2022. Monitoring rights violations based on SOGI and HIV is effective in identifying legal issues, stigma and discrimination, informing recommendations to enhance HIV responses. Our

findings underscore the imperative to address stigma and discrimination not only at individual level but also within community and structural contexts, emphasizing the need for comprehensive interventions.

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COMPETING INTERESTS

The authors have declared that no competing interests exist.

AUTHORS' CONTRIBUTIONS

OK conceptualized and drafted the manuscript, led the content analysis, conducted statistical analysis and interpreted the data. ETk and NM contributed data for the analysis, actively participated in discussions, and critically reviewed and edited the manuscript. The authors assume responsibility for the integrity and accuracy of the data analysis. The final version of the manuscript has been read and approved by all authors.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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SUPPORTING INFORMATION

Additional information may be found under the Supporting Information tab for this article:

File S1: Codebook. The final version of the coding book used in the analysis presented in the article.

RESEARCH ARTICLE

Changes in risk behaviour following a network peer education intervention for HIV prevention among male Tajik migrants who inject drugs in Moscow: a cluster-randomized controlled trial

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Abstract

Introduction: The “Migrants’ Approached Self-Learning Intervention in HIV/AIDS for Tajiks” (MASLIHAT) recruits and trains Tajik labour migrants who inject drugs as peer educators (PEs) in delivering HIV prevention information and encouragement to adopt risk-reduction norms and practices within their diaspora social networks while reducing their own HIV risk.

Methods: The MASLIHAT intervention was tested in Moscow in a cluster-randomized controlled trial with 12 recruitment sites assigned to either the MASLIHAT intervention or an equal-time peer-educator training focused on other health conditions (TANSIHAT). From October 2021 to April 2022, 140 male Tajik migrants who inject drugs were recruited as PEs to attend the 5-session MASLIHAT training or the TANSIHAT non-HIV comparison condition. Each participant in both groups recruited two network members (NMs) who inject drugs with the intent to share with them the information and positive strategies for change they had learned ($n = 280$). All PEs and NMs ($n = 420$) participated in baseline and follow-up interviews at 3-month intervals for 1 year. All received HIV counselling and testing. Modified mixed effects Poisson regressions tested for group differences in injection practices, sexual risk behaviours and heavy alcohol use over time.

Results: At baseline, across both groups, 75% of participants reported receptive syringe sharing (RSS), 42% reported condomless sex and 20% reported binge drinking at least once a month. In contrast to TANSIHAT where HIV risk behaviours remained the same, significant intervention effects that were sustained over the 12 months were observed for receptive syringe and ancillary equipment sharing among both MASLIHAT PEs and NMs ($p < 0.0001$). Significant declines in the prevalence of sexual risk behaviours were also associated with the MASLIHAT intervention ($p < 0.01$), but not the comparison condition. Binge alcohol use was not affected in either condition; the MASLIHAT intervention had a transitory effect on drinking frequency that dissipated after 9 months.

Conclusions: The MASLIHAT peer-education intervention proved highly effective in reducing HIV-related injection risk behaviour, and moderately effective in reducing sexual risk behaviour among both PEs and NMs. Network-based peer education is an important tool for HIV prevention among people who inject drugs, especially in environments that are not amenable to community-based harm reduction.

Keywords: HIV prevention; peer education intervention; cluster-randomized trial; injection drug use; Tajik; migrant worker

Additional information may be found under the Supporting Information tab of this article.

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1 | INTRODUCTION

While significant progress has been made in addressing the AIDS pandemic throughout much of the world, new cases of HIV increased by 48% in eastern Europe and central Asia from 2010 to 2021 [1], with most new cases occurring in the Russian Federation [2]. Although the HIV epidemic in the Russian Federation has become generalized [3], injection drug

use still accounts for about 40% of new cases [1, 4]. Labour migrants who inject drugs while in Russia are at especially high risk for acquiring HIV due to social marginalization and lack of access to healthcare and prevention services [5]. Many migrant workers in Russia originate from the central Asian countries, including Tajikistan—a small country with comparatively lower HIV rates, high poverty and an ongoing opioid epidemic [6–8].

We developed the Migrants' Approached Self-Learning Intervention in HIV/AIDS for Tajiks (MASLIHAT) intervention to address the need for preventive interventions for this population [9]. MASLIHAT is a network-based, peer educator (PE) training intervention developed as a socio-cultural adaptation of the Self-Help in Eliminating Life-Threatening Diseases (SHIELD) model [10–12] to reduce risky drug and sexual behaviour among male Tajik migrants in Moscow who inject drugs. Heavy alcohol use that may contribute to sexual risk through disinhibition is also targeted. Like SHIELD, MASLIHAT is designed to promote the dissemination of information and behavioural risk-reduction modelling through social networks to produce changes in social norms of HIV-related sexual and drug injection risk behaviour. It also draws on Yang's Theory of Migration [13] that emphasizes the need to modify the psychosocial conditions and life circumstances that contribute to risk behaviour. Presently, the intervention targets only male migrants, as the number of female Tajik migrants who inject drugs is quite small, and Tajiks would be uncomfortable discussing sexual risk in a mixed-sex group. Pilot testing in 2018 demonstrated promising results with significant declines in HIV risk behaviour over 6 months among both PE participants and their network members (NMs) with whom they regularly interacted [9].

In the present study, a cluster-randomized parallel groups trial tests the efficacy of the MASLIHAT intervention versus a comparison condition in reducing HIV-related risk behaviour. We adapted an existing health education intervention (Healthy Living) previously developed to serve as a control intervention to create the "Targeted Application of Network and Social Intervention on Health Assistance for Tajiks" (TANSIHAT) as an equal-time health education intervention focusing on other relevant health conditions such as tuberculosis (TB) and cardiovascular disease but not HIV. In both conditions, participants were trained as PEs and referred for HIV counselling and testing at the Moscow HIV Prevention Center [14]. Risk behaviour was assessed at baseline and at 3-month intervals during 1 year of follow-up.

2 | METHODS

Study procedures were reviewed and approved by the Institutional Review Boards of the University of Illinois Chicago, PRISMA Research Center in Tajikistan, and the Moscow Non-government Organization "Bridge to the future." All participants provided written informed consent. All activities and assessments were conducted in Tajik or Russian by male Tajik staff. English-language instruments were translated by PRISMA investigators/staff and independently back-translated to English for verification. PRISMA staff are themselves former Tajik migrant workers and are trained on the importance of treating people who inject drugs (PWID) with dignity and compassion.

2.1 | Recruitment and site assignment

From October 2021 to April 2022, 140 male Tajik migrant workers were recruited and trained as PEs from 12 sites in Moscow: two Tajik diaspora organizations, four bazaars and six construction work sites. To participate as a PE assigned to

either the MASLIHAT intervention or the TANSIHAT comparison condition, prospective participants needed to be a male Tajik migrant aged 18 or older, a current or former PWID, give informed consent, intend to reside in Moscow for the next 12 months to participate in their assigned intervention and follow-up data collection, and willing to recruit two male PWID to participate as NMs for baseline and follow-up interviewing but who would not participate in either condition's educational sessions or activities. NMs ($n = 280$) had to meet the same eligibility criteria as PEs but also: (1) have injected drugs at least once in the last 30 days; and (2) be someone whom the PE sees at least once a week to permit him to share intervention information and encourage normative and behavioural change within their social networks. Participants received the equivalent of \$20.00 in Russian Rubles for their time and transportation costs in participating in intervention sessions (PEs only) and for being interviewed at baseline and follow-up (both PEs and NMs).

To prevent MASLIHAT cross-contamination of the control condition through shared peer networks, the 12 recruitment sites were pair-matched according to site characteristics and randomly assigned to the MASLIHAT versus TANSIHAT condition. Recruiters were blinded as to each site's assignment condition. Site assignment was revealed to the local project coordinator only when it was needed for scheduling intervention sessions.

2.2 | Sample determination

We estimated power in multilevel analyses using PASS 2019 software (v19.0.1) based on effects observed in the pilot study [9] and assuming up to 10% attrition among intervention participants and up to 15% attrition among NMs. With 12 recruitment sites, intra-cluster correlation ($ICC = .05$, $\alpha = .01$ and at least 10 intervention participants per cluster (20 NMs, 30 total), we estimated at least 80% power to detect medium changes in condomless sex, and over 90% power to detect large changes in syringe sharing. For days of alcohol use, with $ICC = 0.3$, we estimated at least 80% power to detect a standardized mean difference ($SMD = 0.70$ for intervention participants (clusters = 10) and $SMD = 0.50$ for NMs (clusters = 20).

2.3 | Intervention sessions

MASLIHAT is a manualized small-group, interactive intervention that relies on peer networks to reduce drug, alcohol and sexual risk behaviours among temporary migrant workers who inject drugs. Migrants in the host country who inject or previously injected drugs are trained as PEs to promote positive HIV risk-reduction norms and behavioural change through role modelling and by sharing what they learned during MASLIHAT training sessions with their at-risk NMs in conversations. The intervention includes five HIV knowledge and skill-building sessions that involve goal setting, role playing, demonstrations, homework and group discussions. These sessions teach participants techniques for personal HIV risk reduction and the communication and outreach skills needed to encourage others at risk for HIV to also adopt them.

MASLIHAT sessions also address general lifestyle, health and safety issues relevant to migrant life [15–22].

The five sessions are: (1) Introduction to MASLIHAT; general risks and safety for Tajik migrant workers; living a healthy lifestyle, resources & organizations serving Tajik migrants; (2) HIV 101; peer communication skills; (3) HIV/STI risk/prevention through hazardous alcohol consumption/unsafe sex; (4) HIV risk/prevention related to drug use; (5) Maintaining a healthier lifestyle; graduation. Homework and case studies help to script PE messages.

The TANSIHAT programme echoes MASLIHAT in style and time commitment over five sessions: (1) Introduction to TANSIHAT; general risks to health and safety; strategies for general risk-reduction and living a healthy lifestyle; available resources; (2) Healthy nutrition and personal hygiene; peer communication skills; (3) Fitness and stress management; promoting a healthy lifestyle through physical exercises and stress management; (4) TB risk and prevention among migrants and preventing transmission to families back home; (5) Maintaining healthier living and risk reduction; graduation.

The intervention sessions for both conditions were delivered in groups of 4–7 at the PRISMA Research Center by experienced group facilitators. MASLIHAT and TANSIHAT sessions were delivered by different facilitators. Sessions were scheduled weekly and each lasted 2 hours. Facilitators recorded attendance and rated participant engagement as “not engaged,” “somewhat engaged” or “highly engaged.” Every session started with a homework check-in. Should a participant miss a session, he received all the session materials and could meet with a session facilitator at a mutually convenient time to ask questions and obtain more information about the missed session. Facilitator presentations and success in stimulating group discussion were observed by PRISMA senior staff and rated on seven facilitator performance dimensions as being poor (0), adequate (1) or good (2).

2.4 | Baseline and follow-up interviews

After giving informed consent, baseline interviews with PEs and NMs were conducted at the PRISMA office in Moscow or a private location of the participant's choosing. Comprehensive locator information was collected from participants to aid with follow-up, including alternate contact information. Following the interview, participants were referred to the Moscow HIV Prevention Center to be tested for HIV and hepatitis C virus (HCV). Anonymized test results were reported to study staff with only a group number to identify the recruitment site. Follow-up interviews were conducted with PEs and NMs at 3-month intervals. All participants were referred for repeat HCV testing following the 6- and 12-month interviews and for HIV testing following the 12-month interview.

2.5 | Measures

The structured baseline questionnaire collected information on socio-demographic characteristics, migration characteristics, alcohol use, injection drug use prior to migration and in the past 6 months in Moscow, sexual risk behaviour, and PWID network and injection risk behaviour.

HIV testing and Serostatus was assessed at baseline and at each follow-up by asking: (a) “Have you ever been tested for HIV?” (Yes/No), and if yes, (b) “What were the results of your most recent HIV test?” (1) HIV Positive (you have HIV), (2) HIV Negative (you don't have HIV) and (3) Decline to answer.

Alcohol use. Binge drinking was assessed with the question from the Alcohol Use Disorders Identification Test (AUDIT) [23, 24], “How often do you have 6 or more drinks on one occasion,” with responses on a 5-point scale from “never” to “daily or nearly daily.” Responses were dichotomized for analysis as “never or less than monthly” versus “at least monthly.” Frequency of alcohol use was measured with the question, “How many days in the past month have you used alcohol, including beer, wine, or vodka?”

Injection risk behaviour. Recent syringe sharing was assessed in response to the question, “In the past 3 months, how often have you used a needle to shoot drugs after someone else used it first?” with response options: never, rarely, less than half the time, about half the time, more than half the time, almost always and always. Responses were dichotomized into a binary measure of having or not having used a shared syringe within the past 3 months.

Sexual risk behaviour. Measures of sexual risk behaviour included condomless sex in the past 3 months, multiple female sex partners and sex with female sex workers (FSWs). Participants were asked for the number of women with whom they had sexual intercourse in the past 30 days, and how many of these were sex workers. Responses were used to create binary measures of multiple female partners and any FSW partner in the past 30 days. Condom use was assessed by asking participants, “how often did you use a condom when having sexual intercourse?” for each of three partner categories: regular female sex partner in Russia, FSW, and other sexual partners not engaged in selling sex. Response categories were “never,” “sometimes,” “often” or “always.” Responses were combined into a binary measure of condomless versus no condomless sex in the past 3 months.

2.6 | Analysis

We tested the effects of the MASLIHAT intervention on the study's primary outcomes of receptive syringe sharing (RSS), condomless sex and binge drinking. We also analysed additional outcomes of ancillary equipment sharing, multiple female sex partners, sex with sex workers and frequency of alcohol use. Mixed effects modified Poisson regression models with random intercepts for participant and network cluster were estimated for each outcome [25, 26]. The modified Poisson model has the advantage of readily providing covariate-adjusted risk ratios and standard errors. Time was included as four dummy variables for 3-, 6-, 9- and 12-month follow-up. We tested a three-way interaction of condition, time and participant type (PE or NM), and non-significant interactions ($p > .10$) were removed from the model. Marginal contrasts tested for intervention effects by participant type. Unadjusted prevalence ratios with 95% confidence intervals were examined for each outcome. The effects of adjusting for covariates identified as having significant associations at baseline were investigated including number of trips to Moscow, time in Moscow on the current trip, age, and level of education.

Table 1. Demographic characteristics of PWID enrolled in the MASLIHAT trial

Variable	Peer educators (n = 140)		Network members (n = 280)	
	Mean (SD)	Range	Mean (SD)	Range
Age	30.7 (6.74)	21–50	29.6 (5.90)	19–49
	n	%	n	%
Recruitment site				
Diaspora organization	24	17.1	48	17.1
Bazaar	44	31.4	88	31.4
Construction site	72	51.4	144	51.4
Area of origin				
Dushanbe	31	22.1	57	20.4
Khatlon	29	20.7	59	21.1
Sughd	13	9.3	31	11.1
Gorno-Badakhshan	54	38.6	105	37.5
Subordinate districts	13	9.3	28	10.0
Education				
Secondary or less	91	65.0	165	58.9
College or technical college	32	22.9	73	26.1
University but no degree	6	4.3	8	2.9
University degree	11	7.9	34	12.1
Marital status				
Not married	65	46.4	111	39.6
Married	14	10.0	38	13.6
Divorced	61	43.6	129	46.1
Missing			2	0.7
How long in Russia this trip				
One year or less	9	6.4	30	10.7
>1 to 2 years	42	30.0	88	31.4
>2 years	86	61.4	156	55.7
Missing	3	2.1	6	2.1
How many trips to Moscow				
One	8	5.7	41	14.6
Two	55	39.3	81	28.9
Three or more	77	55.0	158	56.4
Employment				
Construction	76	54.3	154	55.0
Loading in bazaar	29	20.7	58	20.7
Selling/food service	27	19.3	48	17.1
Other/Missing	8	5.7	20	7.1

Abbreviations: MASLIHAT, “Migrants’ Approached Self-Learning Intervention in HIV/AIDS for Tajiks”; PWID, people who inject drugs; SD, standard deviation.

3 | RESULTS

Table 1 shows the baseline demographic characteristics of PEs (N = 140) and NMs (N = 280) for the entire sample. There were no significant differences between intervention arms, except on marital status (8.6% currently married in MASLIHAT, 16.2% in TANSIHAT; $\chi^2 = 8.53$, $p = 0.014$). The CONSORT diagram in Figure 1 depicts the two groups’ progress through the multiple phases of the study’s parallel randomized trial. The monthly average of drinking days was 5.3 (SD 3.27, Range: 0–20), and 21% reported binge drinking (six or more

drinks at a time) at least once a month. Sexual risk behaviour was common with 42% reporting condomless sex in the past month. Over 75% reported injecting with a previously used syringe in the past 3 months. At baseline, 17% reported they had been tested for HIV, and one participant disclosed being HIV positive; 20% of those tested ($n = 14$) declined to disclose their results. Of the 413 participants who were tested for the study, 28 (6.8%) tested HIV positive. All participants were offered help in obtaining HIV treatment. There were no new HIV acquisitions among participants who were tested during follow-up.

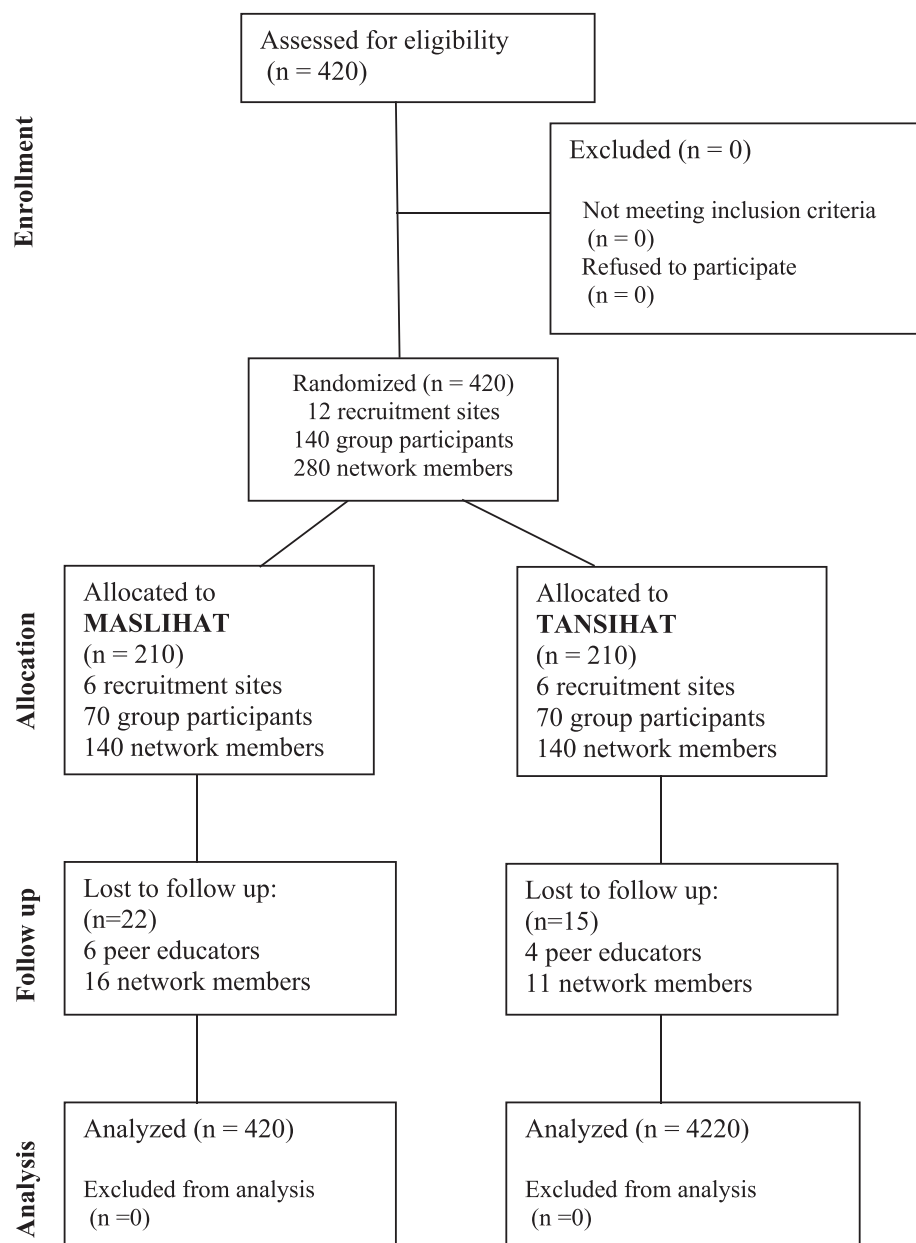


Figure 1. CONSORT diagram of MASLIHAT cluster-randomized trial. Abbreviations: MASLIHAT, Migrants' Approached Self-Learning Intervention in HIV/AIDS for Tajiks; TANSIHAT, Targeted Application of Network and Social Intervention on Health Assistance for Tajiks (comparison condition).

3.1 | Intervention implementation and attendance

All participants attended at least four of the five sessions, and 81% attended all five sessions. Attendance and facilitator ratings of participant engagement were similar across treatment arms. Facilitators received "good" ratings across all dimensions in 98% of sessions with no difference between treatment arms.

3.2 | Follow-up and retention

Over 90% of participants completed all interview waves. Thirty-seven participants (8.8%) were lost to follow-up at 9

($n = 18$) or 12 months ($n = 19$). Loss to follow-up was similar across treatment arms and participant type.

3.3 | Risk behaviour outcomes

Results of the unadjusted Poisson models are shown in Tables 2–4. We used MASLIHAT and PE as the reference groups so that the time effect shows the difference between follow-up and baseline for PEs in the MASLIHAT condition. Covariate-adjusted model results are available in File S1 and marginal predictions are presented graphically in Figures 2–5.

Table 2. Intervention effects on injection risk behaviours, unadjusted mixed effects robust Poisson regression

	Syringe sharing			Equipment sharing		
	IRR	95% CI	p-value	IRR	95% CI	p-value
Time ^a						
3 Months	0.13	0.06, 0.28	<0.001	0.11	0.07, 0.17	<0.001
6 Months	0.09	0.03, 0.22	<0.001	0.11	0.07, 0.18	<0.001
9 Months	0.16	0.08, 0.31	<0.001	0.11	0.06, 0.19	<0.001
12 Months	0.33	0.21, 0.51	<0.001	0.12	0.07, 0.19	<0.001
Arm ^b						
TANSIHAT versus MASLIHAT	1.00	0.79, 1.26	1	0.99	0.82, 1.20	0.919
Participant type ^c						
Network member versus PE	1.18	1.00, 1.39	0.045	1.09	0.97, 1.21	0.156
Arm × Participant type ^d	1.03	0.81, 1.29	0.821	–		
Time × Arm ^e						
3 Months	8.33	3.85, 18.02	<0.001	10.55	6.69, 16.65	<0.001
6 Months	13.75	5.22, 36.22	<0.001	10.73	6.31, 18.24	<0.001
9 Months	7.57	3.71, 15.43	<0.001	10.88	6.18, 19.17	<0.001
12 Months	3.53	2.21, 5.64	<0.001	10.64	6.44, 17.68	<0.001
Time × Participant type ^f						
3 Months	0.71	0.32, 1.56	0.390	–		
6 Months	1.16	0.43, 3.14	0.763			
9 Months	0.91	0.49, 1.69	0.774			
12 Months	0.69	0.46, 1.02	0.062			
Time × Arm × Participant type ^g						
3 Months	1.38	0.62, 3.06	0.432	–		
6 Months	0.77	0.29, 2.09	0.612			
9 Months	0.96	0.52, 1.80	0.911			
12 Months	1.35	0.89, 2.04	0.154			
Random intercept variances	var	SE		var	SE	
cluster	0	0		0	0	
subject	0	0		0	0	
N	420			420		
clusters	140			140		
observations	2039			1973		

Abbreviations: CI, confidence interval; IRR, incidence rate ratio; MASLIHAT, “Migrants’ Approached Self-Learning Intervention in HIV/AIDS for Tajiks”; NM, network member; PE, peer educator; SE, standard error; TANSIHAT, Targeted Application of Network and Social Intervention on Health Assistance for Tajiks (comparison condition); var, variance.

^aEffect of time for PEs in MASLIHAT arm.

^bDifference between arms for PEs at baseline.

^cDifference between PEs and NMs in MASLIHAT arm at baseline.

^dDifference between arms for NMs at baseline.

^eDifference between arms for PEs at follow-up time points.

^fDifference between PEs and NMs in MASLIHAT arm at follow-up time points.

^gDifference between PEs and NMs in TANSIHAT (control) arm at follow-up time points.

The unadjusted results for injection risk behaviour are shown in Table 2. The time × condition interaction for RSS was significant for both MASLIHAT PEs (Chi2[4] = 105.91, $p < 0.0001$) and NMs (Chi2[4] = 256.12, $p < 0.0001$). Significant declines in RSS were sustained over 12 months of follow-up (see Figure 2). Similar results were seen for ancillary equipment sharing for PEs (Chi2[4] = 118.89, $p < 0.0001$) and NMs (Chi2[4] = 134.74, $p < 0.0001$). Covariate adjustment had little effect on estimates and did not alter the conclusions.

The results of the unadjusted Poisson models for sexual risk behaviour are shown in Table 3. There were initially significant declines in the prevalence of condomless sex among MASLIHAT versus TANSIHAT PEs (Chi2[4] = 14.64, $p = 0.0055$) and NMs (Chi2[4] = 53.39, $p < 0.0001$). At 12-month follow-up, the unadjusted prevalence of condomless sex was only modestly lower than baseline (PE: $dy/dx = -0.14$, $z = -2.21$, $p = 0.027$; NM: $dy/dx = -0.10$, $z = -1.94$, $p = 0.053$). When adjusted, however, for age and level of education (see File S1), the decline in prevalence of condomless sex appeared

Table 3. Intervention effects on sexual risk behaviours, unadjusted mixed effects robust Poisson regression

	Any condomless sex			Multiple sex partners			Sexual activity w/sex workers		
	IRR	95% CI	p-value	IRR	95% CI	p-value	IRR	95% CI	p-value
Time ^a									
3 Months	0.50	0.34, 0.73	<0.001	0.28	0.17, 0.45	<0.001	0.74	0.66, 0.84	<0.001
6 Months	0.60	0.42, 0.86	0.005	0.27	0.17, 0.44	<0.001	0.78	0.68, 0.89	<0.001
9 Months	0.65	0.45, 0.95	0.026	0.26	0.15, 0.45	<0.001	0.69	0.57, 0.84	<0.001
12 Months	0.67	0.46, 0.97	0.035	0.34	0.19, 0.61	<0.001	0.75	0.61, 0.92	0.005
Arm ^b									
TANSIHAT versus MASLIHAT	1.75	1.24, 2.46	0.001	1.02	0.63, 1.64	0.951	1.06	0.74, 1.52	0.752
Participant type ^c									
Network member versus PE	1.02	0.75, 1.40	0.894	1.17	0.80, 1.70	0.43	1.69	1.26	2.25
Arm × Participant type ^d	0.39	0.25, 0.62	<0.001	–			–		
Time × Arm ^e									
3 Months	1.67	1.10, 2.53	0.018	3.04	1.96, 4.71	<0.001	1.39	1.18, 1.63	<0.001
6 Months	1.81	1.24, 2.62	0.002	3.61	2.32, 5.63	<0.001	1.45	1.21, 1.73	<0.001
9 Months	1.56	1.05, 2.32	0.026	3.78	2.31, 6.18	<0.001	1.75	1.38, 2.22	<0.001
12 Months	1.68	1.13, 2.49	0.010	3.97	2.25, 7.00	<0.001	1.70	1.31, 2.19	<0.001
Time × Participant type ^f									
3 Months	0.53	0.31, 0.93	0.027	1.17	0.83, 1.65	0.370	–		
6 Months	1.19	0.76, 1.89	0.445	1.07	0.74, 1.52	0.729			
9 Months	1.11	0.75, 1.63	0.609	1.04	0.70, 1.55	0.832			
12 Months	1.14	0.75, 1.73	0.550	0.72	0.49, 1.05	0.091			
Time × Arm × Participant type ^g									
3 Months	2.14	1.16, 3.94	0.015	–			–		
6 Months	1.22	0.72, 2.05	0.461						
9 Months	1.60	1.00, 2.54	0.049						
12 Months	1.77	1.06, 2.97	0.030						
Random intercept variances	var	SE		var	SE		var	SE	
cluster	0.18	0.065		0.89	0.288		0.37	0.143	
subject	0.24	0.094		1.37	0.322		0.92	0.213	
N	420			420			420		
clusters	140			140			140		
observations	2043			2043			2040		

Abbreviations: CI, confidence interval; IRR, incidence rate ratio; MASLIHAT, "Migrants' Approached Self-Learning Intervention in HIV/AIDS for Tajiks"; NM, network member; PE, peer educator; SE, standard error; TANSIHAT, Targeted Application of Network and Social Intervention on Health Assistance for Tajiks (comparison condition); var, variance.

^aEffect of time for PEs in MASLIHAT arm.

^bDifference between arms for PEs at baseline.

^cDifference between PEs and NMs in MASLIHAT arm at baseline.

^dDifference between arms for NMs at baseline.

^eDifference between arms for PEs at follow-up time points.

^fDifference between PEs and NMs in MASLIHAT arm at follow-up time points.

^gDifference between PEs and NMs in TANSIHAT (control) arm at follow-up time points.

sustained (see Figure 3). The prevalence of multiple female sex partners declined significantly following the intervention and in contrast to the control condition for PEs ($\text{Chi}^2[4] = 18.10$, $p = 0.0012$) and NMs ($\text{Chi}^2[4] = 28.01$, $p < 0.0001$) and was sustained over 12 months (see Figure 4). The prevalence of sex with sex workers also declined for MASLIHAT PEs ($\text{Chi}^2[4] = 17.77$, $p = 0.0014$) and NMs ($\text{Chi}^2[4] = 24.23$, $p = 0.0001$) and the effect was sustained over 12 months. Covariate adjustment had little effect on estimates

of multiple partners or commercial sex and did not alter the conclusions.

The results of the unadjusted Poisson models for alcohol use measures are shown in Table 4. The intervention had no effect on monthly binge drinking ($\text{Chi}^2[8] = 14.48$, $p = 0.07$). Frequency of alcohol use (days drinking past 30 days) initially decreased among MASLIHAT versus control PEs ($\text{Chi}^2[4] = 14.56$, $p = 0.0057$) with less effect among NMs ($\text{Chi}^2[4] = 10.98$, $p = 0.0268$). At 9-month

Table 4. Intervention effects on alcohol use, unadjusted mixed effects robust Poisson regression

	Monthly binge alcohol			Days drinking alcohol		
	IRR	95% CI	p-value	IRR	95% CI	p-value
Time ^a						
3 Months	0.70	0.48, 1.02	0.065	0.86	0.79, 0.94	0.001
6 Months	0.65	0.45, 0.94	0.022	0.86	0.77, 0.95	0.004
9 Months	0.63	0.43, 0.92	0.016	1.14	0.91, 1.43	0.264
12 Months	0.67	0.47, 0.95	0.026	1.19	0.98, 1.45	0.085
Arm ^b						
TANSIHAT versus MASLIHAT	2.59	0.95, 7.06	0.063	1.07	0.79, 1.44	0.665
Participant type ^c						
Network member versus PE	2.44	1.00, 5.98	0.051	1.34	1.06, 1.68	0.013
Arm × Participant type ^d	0.20	0.06, 0.68	0.010	0.89	0.67, 1.18	0.429
Time × Arm ^e						
3 Months	1.28	0.91, 1.79	0.154	1.15	1.02, 1.29	0.024
6 Months	1.33	0.95, 1.86	0.092	1.20	1.03, 1.40	0.017
9 Months	1.29	0.93, 1.80	0.125	0.89	0.68, 1.17	0.413
12 Months	1.30	0.94, 1.78	0.110	1.04	0.81, 1.33	0.763
Time × Participant type ^f						
3 Months	0.95	0.70, 1.28	0.723	1.00	0.91, 1.09	0.919
6 Months	1.00	0.75, 1.33	0.985	1.06	0.95, 1.18	0.315
9 Months	1.06	0.77, 1.44	0.746	0.91	0.75, 1.11	0.360
12 Months	1.01	0.76, 1.34	0.967	0.91	0.76, 1.09	0.310
Time × Arm × Participant type ^g						
3 Months	—			0.96	0.85, 1.09	0.524
6 Months				0.89	0.76, 1.04	0.131
9 Months				1.08	0.84, 1.38	0.569
12 Months				0.97	0.76, 1.24	0.804
Random intercept variances	var	SE		var	SE	
cluster	0	0		0.16	0.08	
subject	7.12	0.82		0.13	0.040	
N	420			420		
clusters	140			140		
observations	2036			2038		

Abbreviations: CI, confidence interval; IRR, incidence rate ratio; MASLIHAT, “Migrants’ Approached Self-Learning Intervention in HIV/AIDS for Tajiks”; NM, network member; PE, peer educator; SE, standard error; TANSIHAT, Targeted Application of Network and Social Intervention on Health Assistance for Tajiks (comparison condition); var, variance.

^aEffect of time for PEs in MASLIHAT arm.

^bDifference between arms for PEs at baseline.

^cDifference between PEs and NMs in MASLIHAT arm at baseline.

^dDifference between arms for NMs at baseline.

^eDifference between arms for PEs at follow-up time points.

^fDifference between PEs and NMs in MASLIHAT arm at follow-up time points.

^gDifference between PEs and NMs in TANSIHAT (control) arm at follow-up time points.

follow-up, drinking days increased significantly with levels rising above baseline at 12 months (see Figure 5). Covariate adjustment had little effect on estimates and did not alter the conclusions.

4 | DISCUSSION

The MASLIHAT intervention for HIV prevention is a network-based peer education intervention, tailored for male Tajik

migrants who inject drugs while working in Russia. In this cluster-randomized controlled trial, we found significant reductions in self-reported injection and sexual risk behaviours associated with intervention participation when compared with a time-matched control intervention with referral in both conditions to HIV testing and counselling. Changes in behaviour that persisted for 12 months were reported by both PEs who attended the MASLIHAT intervention sessions and their NMs to whom they relayed the information they had learned. Reductions in injection risk

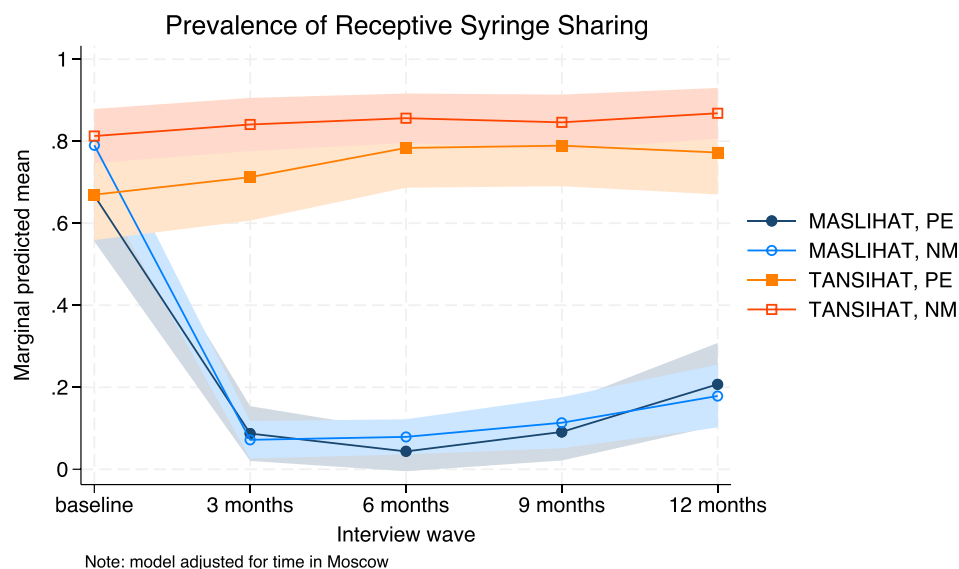


Figure 2. Predicted prevalence of receptive syringe sharing. Marginal predictions of receptive syringe sharing with 95% confidence intervals, by time, condition and participant type, adjusted for time in Moscow. Abbreviations: MASLIHAT, intervention condition; NM, network members; PE, peer educators; TANSIHAT, control condition.

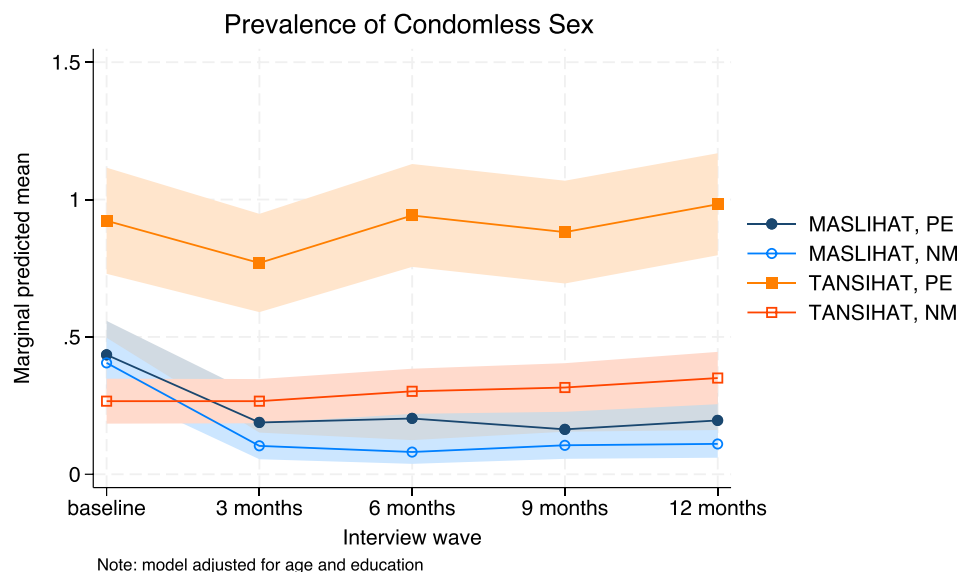


Figure 3. Predicted prevalence of condomless sex. Marginal predictions of any condomless sex with 95% confidence intervals, by time, condition and participant type, adjusted for age and level of education. Abbreviations: MASLIHAT, intervention condition; NM, network members; PE, peer educators; TANSIHAT, control condition.

behaviour among both PEs and NMs were quite dramatic, while changes in sexual risk behaviour were less pronounced. Peer network intervention studies in the United States similarly found stronger results for injection than for sexual risk behaviour [27–29].

The observed differences in positive change between injection versus sexual behaviour may be due in part to the situations and settings in which they occur. Injection drug use is a shared behaviour, while sexual encounters typically occur in private. It is not surprising that network norms of risk reduc-

tion are more likely to influence behaviours conducted in an observable space. It is also possible that condom use is not sustained once a monogamous sexual relationship is established [30]. A more nuanced definition of sexual risk may better capture behavioural changes.

Although the intervention aimed to reduce heavy alcohol use associated with HIV risk behaviour through disinhibition, we saw only transitory reductions in the frequency of drinking and no effect on binge alcohol use. While there was a slight decline in binge drinking in both groups, the decline was

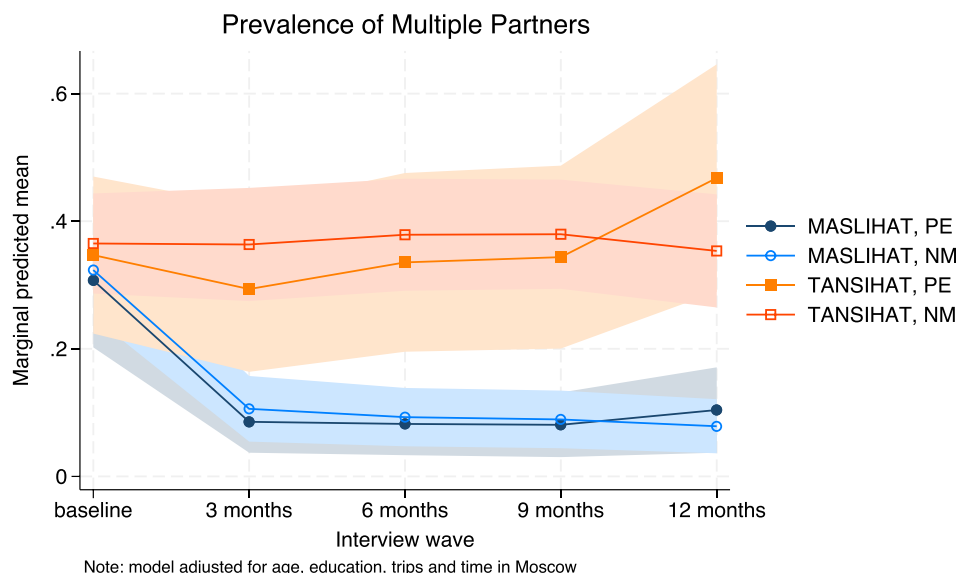


Figure 4. Predicted prevalence of multiple partners. Marginal predictions of multiple female partners with 95% confidence intervals, by time, condition and participant type, adjusted for trips to Moscow, time in Moscow, age and level of education. Abbreviations: MASLIHAT, intervention condition; NM, network members; PE, peer educators; TANSIHAT, control condition.

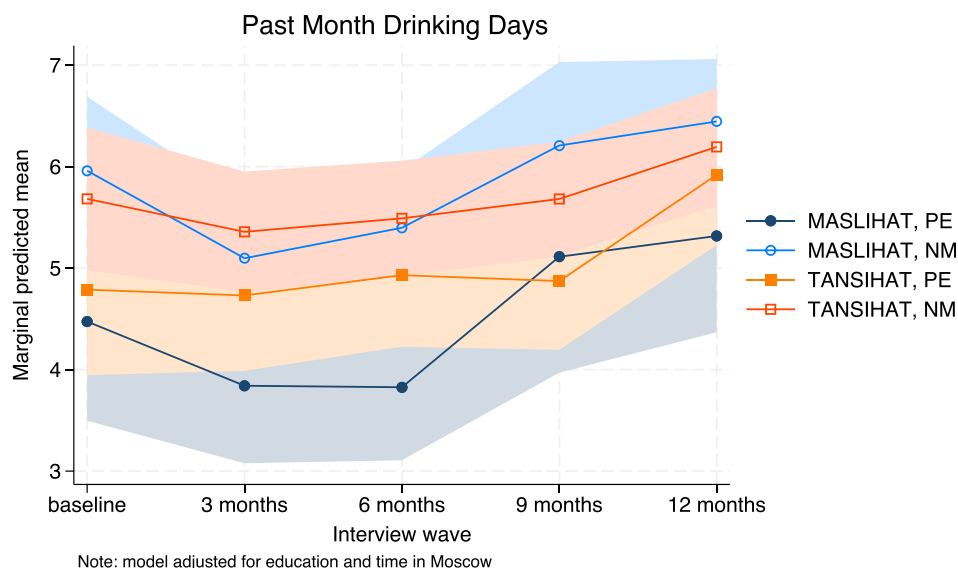


Figure 5. Predicted drinking days. Marginal predictions of days drinking alcohol in the past month with 95% confidence intervals, by time, condition and participant type, adjusted for time in Moscow and level of education. Abbreviations: MASLIHAT, intervention condition; NM, network members; PE, peer educators; TANSIHAT, control condition.

only nominally greater in the MASLIHAT group (20 percentage points vs. 10 percentage points in TANSIHAT). Additional analyses are warranted to explore if the observed changes in participant alcohol use are concentrated among participants who have problem drinking (e.g. high AUDIT scores at baseline). Since the TANSIHAT intervention also teaches about healthy lifestyles including safer alcohol use, there may not be a detectable difference between groups. Nevertheless, over half of all participants continued to report binge drinking at least once a month. This suggests that a different approach

may be needed to address hazardous drinking. The observed increase in drinking frequency at 9 months roughly coincides with the Russian invasion of Ukraine and subsequent sanctions against Russia. These sanctions affected Tajik migrants both economically and socially. The added stress that Tajik migrants likely experienced during this turbulent period may have increased their level and frequency of alcohol consumption.

Community-based programmes employing peer outreach workers (peer-led outreach) have proved successful in chang-

ing behaviour and disseminating prevention information to PWID in other countries [31–33]. Meanwhile, peer network interventions have been tested with PWID in the United States, Vietnam, Thailand and in St. Petersburg, Russia, but not with temporary labour migrants [26, 29, 34–37]. The MASLIHAT intervention is distinctive in being culturally adapted for Tajik male migrant workers at risk for HIV through injecting drugs and in addressing the challenges they face due to social marginalization and economic disadvantage. The MASLIHAT intervention is potentially generalizable to migrant populations of PWID in other Russian cities and other countries if adapted for cultural context and the local situation just as we adapted SHIELD to fit the social environment and life circumstances of Tajik migrants in Moscow [9].

4.1 | Limitations

The intervention was tested with male migrants only, and did not include any assessment of same-sex behaviour. Due to the strong social stigma among Tajik migrants towards same-sex behaviour, its prevalence and HIV risks are difficult to assess reliably. Additional work that is population-appropriate and culturally acceptable is required to evaluate MASLIHAT's impact on Tajik migrant male-to-male sexual risk behaviour. The primary outcomes in this study relied on self-reported behaviour. Self-reports cannot be verified and can be subject to the demand characteristics of the intervention or to social desirability bias. The results of HIV testing were not individually identifiable, and self-disclosure during follow-up was inconsistent. Consequently, HIV status could not be included in the regression models predicting risk behaviour.

5 | CONCLUSIONS

The MASLIHAT peer-education intervention has proved highly effective in reducing HIV risk through injection drug use and moderately effective in reducing sexual risk among male Tajik intervention participants and their NMs. Given its demonstrated success, it is likely that the MASLIHAT intervention model if culturally adapted holds the potential for increasing HIV prevention among other central Asia migrant populations known to inject drugs in Russia and in other global destination countries where populations of migrant PWID are at high risk for acquiring HIV.

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COMPETING INTERESTS

The authors have no competing interests to declare.

AUTHORS' CONTRIBUTIONS

JAL, MEM-A and MB contributed to the study conception and design. Material preparation and data collection were performed by JJ and CML. Data analysis was conducted by MEM-A and CML. The first draft of the manuscript was written by MEM-A and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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DISCLAIMER

The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

DATA AVAILABILITY STATEMENT

The datasets supporting the findings of this study are available in the Open Science Framework repository. Project: MASLIHAT Randomized Controlled Trial [DOI: 10.17605/OSF.IO/7G3YH]. Data link: https://osf.io/krjqs/?view_only=7c93ea8cf8384dce91b2b531000e63e3j.

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SUPPORTING INFORMATION

Additional information may be found under the Supporting Information tab for this article:

File S1: Additional tables

RESEARCH ARTICLE

A citizen science approach to develop a digital intervention to reduce HIV stigma and promote HIV self-testing among adolescents and young adults: a mixed methods analysis from Kazakhstan

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Abstract

Introduction: Kazakhstan has one of the fastest-growing HIV epidemics in the world, with increasing rates among adolescents and young adults (AYA). Innovative strategies are needed to increase HIV testing uptake and decrease HIV stigma among AYA. Citizen science, defined as the active engagement of the general public in scientific research tasks, promotes and facilitates community engagement throughout the research process. This citizen science study used crowdsourcing to engage AYA in Kazakhstan to develop a digital intervention to reduce HIV stigma and promote HIV self-testing. Our objectives in this paper are to describe the approach used, its feasibility and acceptability, and AYA motivations for and lessons learned collaborating on the study.

Methods: From October 2021 to July 2022, in collaboration with a Community Collaborative Research Board and a Youth Advisory Board, we developed an open call requesting multimedia submissions to reduce HIV testing stigma. Eligible submissions were separated by age group (13–19 or 20–29 years) and judged by a panel composed of AYA ($n = 23$), healthcare professionals ($n = 12$), and representatives from the local government and non-governmental organizations ($n = 17$). Each entry was reviewed by at least four judges and ranked on a 5-point scale. The top 20 open call contestants were asked to submit self-recordings sharing their motivation for and experience participating in the contest and lessons learned. Descriptive statistics were calculated for quantitative data. Qualitative data were coded using open coding.

Results: We received 96 submissions from 77 youth across Kazakhstan. Roughly, three-quarters ($n = 75/96$) of entries met judging eligibility criteria. Of the eligible entries, over half ($n = 39/75$) scored 3.5 or higher on a 5-point scale (70.0%). The most frequent types of entries were video ($n = 36/96$, 37.5%), image ($n = 28/96$, 29.2%) and text ($n = 24/96$, 25.0%). AYA's primary motivations for collaborating on the study included a desire to improve society and help youth. The main challenges included creating content to address complex information using simple language, finding reliable information online and technological limitations.

Conclusions: Crowdsourcing was feasible and highly acceptable among AYA in Kazakhstan. Citizen science approaches hold great promise for addressing the increasingly complex health and social challenges facing communities today.

Keywords: adolescents; stigma; intervention; testing; low- and middle-income countries; HIV

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1 | INTRODUCTION

Eastern Europe and central Asia (EECA) has the world's fastest-growing HIV epidemic with a 43.0% increase in incident cases of HIV acquisition from 2010 to 2020 [1] and for adolescents and young adults (AYA) rates are projected to

increase 27.5% by 2030 [2]. Within EECA, Kazakhstan has the largest increase in incident cases of HIV [1], with a 132.7% increase in HIV incidence among AYA from 2018 to 2020 [3] coupled with low HIV testing rates (in 2015, 22.0% female; 15.0% male AYA tested) [4, 5]. Low uptake of HIV testing is due to a number of factors including perceived low risk of

HIV acquisition, inconvenient testing locations and fear of HIV stigma [6–10]. Many in Kazakhstan are afraid to be tested due to concerns of severe discrimination if they test positive for HIV [7, 11–13]. In Kazakhstan, HIV testing is traditionally administered at city AIDS Centres, where it is obvious individuals are receiving HIV services. HIV self-test kits recently became available in Kazakhstan, but are predominately targeted at men who have sex with men and the messaging may not resonate with AYA. Providing AYA with HIV self-test kits allows them to access testing in a private location, thereby reducing the fear of involuntary disclosure of perceived HIV serostatus or assumed related sexual behaviours or substance use. AYA-tailored messaging is needed to increase HIV testing in this group.

Innovative strategies are needed to generate tailored messaging and reduce HIV testing stigma among AYA in Kazakhstan. Citizen science is the active engagement of the general public in scientific research tasks [14]. Citizen science operates under a horizontal approach where community members are considered competent in-the-field experts [15]. It can engage vulnerable communities and promote health equity [16]. Not relying solely on public health experts fosters innovation and greater inclusion of perspectives from diverse community members, increasing ownership, relevance and sustainability of interventions [17].

Citizen science utilizes participatory methods, such as crowdsourcing, which engages a group of people to develop and share solutions to a problem [18]. Citizen science can be an effective way to develop community-based solutions for a wide range of societal and health challenges, including HIV stigma [14]. Crowdsourcing often utilizes digital technologies, which have been shown to improve a variety of HIV-related outcomes, including promoting HIV testing [19] and antiretroviral therapy adherence [20]. Digital technologies have also shown promise in reducing HIV stigma among healthcare providers [21] and internalized HIV stigma among people living with HIV (PLWH) [22].

The JasSpark Project (meaning “Young Spark” in the Kazakh language) is a citizen science study to engage AYA in Kazakhstan to develop a digital intervention to reduce HIV stigma and promote HIV self-testing. The objectives of this paper are to describe (1) the citizen science approach used, (2) the feasibility and acceptability of using this approach to develop a digital intervention to reduce HIV stigma, and (3) AYA’s perspectives on their motivations and learnings collaborating in the study.

2 | METHODS

Our study used crowdsourcing to engage AYA in Kazakhstan to develop a digital HIV stigma reduction and HIV self-testing intervention package. To address the first objective, we describe the process of implementation, including modifications that occurred during the study. To assess feasibility and acceptability, we describe Community Collaborative Research Board (CCRB) and Youth Research Collaborative (YRC) participation and the number and quality of open call submissions received. To assess AYA perspectives, we describe the findings from video recordings solicited from contestants with crowd-

sourcing entries ranked in the top 20. Descriptive statistics were calculated using SPSS (v28.0).

2.1 | Description of approach used

We launched an online crowdsourcing open call among AYA across Kazakhstan to develop intervention materials in Russian and Kazakh languages. The study was informed by the Theory of Planned Behavior, which posits that the intention to test for HIV is influenced by attitudes about HIV testing (including stigmatizing attitudes), perceived need, and an evaluation of the risks and benefits of testing [23, 24]. We used a Citizen Science Framework [25] integrated with stigma manifestations from the HIV Stigma Framework [26] to guide the study (see Figure 1).

2.1.1 | Establishment and meetings with the CCRB and YRC

AYA were involved in the JasSpark study through the team’s YRC, which was comprised of two separate groups of youth. The first was recruited from non-governmental organizations (NGOs) focusing on HIV among youth to partner on the study as part of the CCRB. These were AYA who were living with HIV and/or were engaged in youth activism in Kazakhstan ($n = 8$). As part of their role, with the other CCRB members, these AYA were responsible for engaging in more high-level decision-making, including the co-development of study procedures, strategies for the open call, judging submissions and co-development of a dissemination plan. Due to high interest from AYA not on our CCRB, we expanded participation to additional youth volunteers ($n = 25$). This second group consisted of AYA collaborators who heard about the study via word-of-mouth from CCRB members and Global Health Research Center of Central Asia (GHRCCA) staff and through announcements about the study at local universities, youth NGOs and on social media. The majority of volunteers in this second group were not living with HIV. AYA volunteers collaborated on a number of day-to-day study development aspects, including managing study social media accounts, co-creating promotional materials for the study, providing feedback on the design of the submission portal and pilot testing it, and co-designing and testing crowdsourcing procedures. Some AYA volunteers also helped judge crowdsourcing entries. AYA who helped judge entries received compensation for their time spent judging (27,000 tenge, ~\$60 USD). AYA were not financially compensated for involvement in other study activities. All AYA assisting with the study received a certificate of collaboration.

Our CCRB was comprised of the eight AYA mentioned above and representatives from youth local and international NGOs; Kazakhstan city, provincial and national AIDS Centres; youth health clinics; and media specialists working with youth. We had no strict selection criteria for the CCRB, but aimed to include a broad spectrum of professionals involved in working with youth. Given GHRCCA’s long-standing research presence in the region, research staff had many existing connections with NGO, health agency and other organization staff that work with youth. Many CCRB members had previous experience serving on CCRBs or collaborating on research,

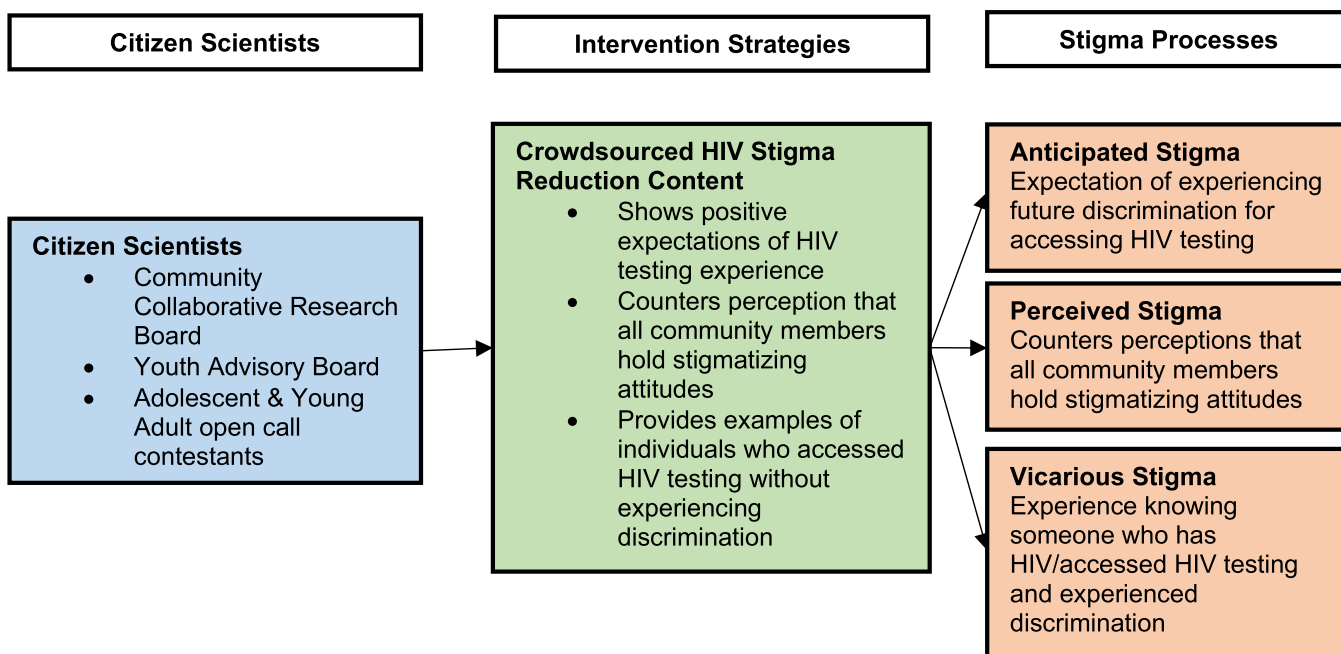


Figure 1. Citizen science study framework.

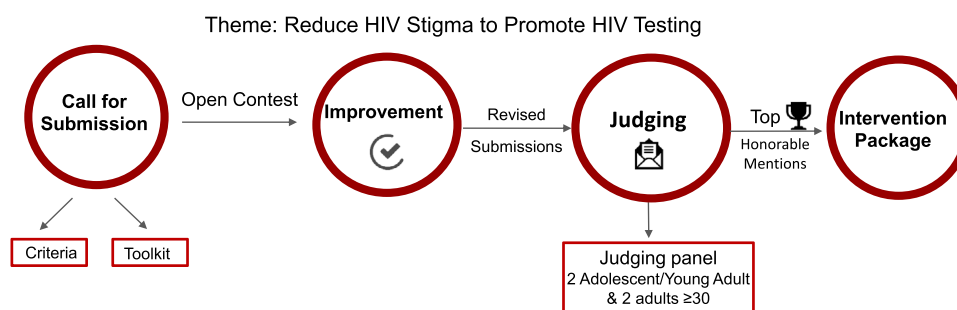


Figure 2. Develop a crowdsourced intervention package.

though the majority of AYA CCRB members did not have prior research collaboration experience. CCRB members were offered 27,000 tenge (~\$60 USD) compensation for their time and effort.

We worked with our CCRB to co-create a solution that would allow for efficient collaboration and was mutually feasible and convenient for all. We had online meetings via Zoom and documentation was shared via email. We created a WhatsApp group based on feedback from AYA CCRB members to provide another outlet for sharing ongoing feedback and collectively discuss research process issues. To facilitate co-creation with youth volunteers [15], we created a separate WhatsApp group and Telegram channel with the AYA volunteers and messaged them multiple times a week.

CCRB members and AYA volunteers received training on study procedures, defining stigma and judging processes. Attendance at meetings was tracked. Utilization of the diverse talents and strengths of our citizen collaborators greatly improved the development of study materials and the flow of study procedures. Citizen collaborators exhibited strong

enthusiasm for the study, including significant in-kind contributions of time and skills, requests by organizations to share crowdsourced materials on their websites, and positive feedback from contestants and volunteers with requests to become involved in other studies.

2.1.2 | Development of intervention materials: crowdsourcing open call

Our collaborative process (Figure 2) began with posting an open call on our study website [27] and various social media channels (e.g. Instagram, Tiktok, Facebook, WhatsApp, Telegram) and through youth events (in-person and online). We developed a national crowdsourcing open call, inviting AYA ages 13–29 years living in Kazakhstan to submit multimedia entries. YRC members created a video to promote the contest and managed study social media accounts. CCRB and YRC members provided feedback on the study website and participated in livestream events to promote and provide more information about the contest. The call focused on developing

submissions to reduce HIV stigma to promote HIV self-testing among at-risk AYA in Kazakhstan. It contained a toolkit with basic information about stigma and HIV, as well as a list of free software and resources to aid in the development of materials. Due to the presence of stigmatizing content in early submissions, we added additional information about avoiding stigmatizing language based on guidelines from HIV-focused organizations (e.g. UNAIDS, UNICEF) to the open call instructions.

To be eligible to submit, AYA had to be 13–29 years old and live in Kazakhstan. They were allowed to submit multiple submissions, either individually or as a group. Eligible submission formats included video, audio, text, images/photos and other multimedia content (e.g. online games, webpages, crossword puzzles). Submissions could be in Russian or Kazakh. Prior to submission, all contestants had to complete a Multimedia Release Form (also signed by a parent for AYA under age 18) and Contestant Agreement providing their permission to use their content as part of a research study and in presentations and agreeing they would postpone publishing their materials until after completion of the scientific study. AYA in the YRC were eligible to submit entries to the crowdsourcing open call, but none submitted.

All submissions were screened for eligibility and the presence of stigmatizing content prior to judging. Each entry was first reviewed by two GHRCCA research staff (OB, DG), and then all entries were reviewed by the Kazakhstan-based PI (GM). Contestants who had entries with stigmatizing content were provided feedback by research staff via their preferred communication method (e.g. WhatsApp, email) and given a chance to revise and resubmit entries. Those who chose to resubmit had only their revised entry judged, while those who chose not to resubmit had their original entry judged.

Eligible submissions were divided by age group (13–19 years old or 20–29 years old) for evaluation by a judging panel consisting of Kazakhstani AYA ($n = 23$), healthcare professionals ($n = 12$), and representatives from the local government and NGOs ($n = 17$). Each entry was judged by two AYA in our YRC (volunteers and AYA CCRB members) and by two other CCRB community partners (i.e. AIDS Centre, youth clinic or NGO staff). To obtain diverse perspectives while easing judging burden, each judge rated a maximum of five entries, thus all entries were not rated by the same four judges. We distributed entries across judges to ensure each judge received a comparable mix of different content types (e.g. video, image). Entries were ranked on a 5-point scale based on four judging criteria used in previous crowdsourcing studies [28, 29]: (1) potential to reduce HIV stigma to increase HIV testing; (2) innovation; (3) relevancy to youth; and (4) overall impression. Entries were considered high-quality if they scored an average of 3.5 or higher on a 5-point scale between the four judging scores. All contestants received participation certificates. A virtual awards ceremony was conducted to honour awardees. First place was awarded for the top Russian and Kazakh language entries in each age category (13–19 years and 20–29 years) and received 220,000 tenge (~\$485 USD). Second-place entries in each age category received 132,000 tenge (~\$290 USD) and third-place entries received 67,000 tenge (~\$145 USD). Seven-

teen contestants received honourable mentions and received 27,000 tenge (~\$60 USD). Multimedia content from winning submissions were combined to form the intervention package that would be tested in a subsequent randomized control trial. Final intervention materials were adjusted for clarity and to correct errors.

To explore the motivations and learnings of AYA collaborators, we messaged the top 20 open call contestants (determined via the 10 highest average judging scores in each age category) and asked them to submit self-recordings responding to the prompts: (1) Why did you decide to take part in this competition? (2) What new things did you learn while working on your content? (3) What was the hardest thing about creating content? Due to resource limitations, we were not able to gather feedback from all 77 contestants. The top 20 entries included entries in both Russian and Kazakh and across media types (e.g. video, image, text). Submission of self-recordings was optional. Interested contestants ($n = 13$) sent self-recorded videos via a messaging app to GHRCCA research staff. An initial coding structure was developed based on the prompts sent to the contestants, and then refined through an iterative review process by the research team. The coding of each recording was conducted by at least three members of the research team. The data collection process (from initial meetings with the CCRB to the sharing of self-recordings) was conducted between October 2021 and July 2022. All study procedures were reviewed and approved by Columbia University's Institutional Review Board and Al-Farabi Kazakh National University's Ethics Committee.

3 | RESULTS

3.1 | Assessing feasibility and acceptability

3.1.1 | CCRB and YRC feasibility and acceptability

The CCRB ($n = 25$, including 8 AYA; 20.0% male, 80.0% female, age range 14–73) met twice before launching the open call to determine content and procedures. Attendance was high—96.0% ($n = 24$) during the first meeting and 80.0% ($n = 20$) during the second meeting. We held a third meeting with the CCRB to review judging procedures (attendance 80.0%, $n = 20$). Seven of the eight AYA CCRB members participated in the judging process. CCRB members were invited to attend the virtual awards ceremony following the judging process (52.0% attended, $n = 13$). CCRB members spent an average of 8–10 hours contributing to the study. Seven of the eight AYA CCRB members also served as AYA volunteers. AYA volunteers ($n = 25$, 60.0% male, 40.0% female, age range 14–31) were highly active in collaborating on the study; of the 25 volunteers, 23 (92.0%) helped conduct at least one component of the study (e.g. develop promotional materials, disseminate study information via social media, participate in judging). Among the AYA volunteers who were not CCRB members, six served as judges. The time AYA volunteers spent collaborating on the study ranged widely. On the low end, some partners spent a few hours total on all activities, while on the high end, partners spent several hours each week over the duration of the study period.

3.1.2 | Open call feasibility and acceptability

During the 4-month open call period, 3412 individuals visited the website. We received 96 submissions from 77 youth (28.6% male, 71.4% female) across Kazakhstan. Eleven youth submitted two entries and four submitted three entries. Nearly, two-thirds (64.6%, $n = 62/96$) of entries were from contestants between ages 13 and 19.

Roughly, three-quarters ($n = 75/96$) of entries met judging eligibility criteria. Entries were excluded if they were unrelated to HIV testing or stigma reduction, were low quality, plagiarized and/or had highly stigmatizing content. The average score for all entries was 3.4 on a 5-point scale. Of the eligible entries, over half ($n = 39/75$) scored 3.5 (70.0%) or higher. Inter-rater agreement between the judges was low (Fleiss' kappa = 0.05, $p = 0.04$). The most frequent types of entries were video ($n = 36/96$, 37.5%), image ($n = 28/96$, 29.2%) and text ($n = 24/96$, 25.0%), with a few audio ($n = 3/96$, 3.1%) and other ($n = 5/96$, 5.2%) entries. Thirty contestants had stigmatizing content or misinformation in their submissions. Stigmatizing content included stigmatizing language (e.g. HIV-infected), stigmatizing images (e.g. blood and skulls), and misinformation and exaggerated fears around HIV transmission (e.g. high risk of HIV acquisition in nail salons). Of the 30 contestants who received feedback on stigmatizing content, 10 revised and resubmitted their entries, and 80.0% of resubmissions ($n = 8/10$) no longer contained stigmatizing information.

3.2 | AYA collaborator motivations and learning

Thirteen out of 20 top contestants sent self-recordings. AYA described their motivations for participating, lessons learned from participation and challenges creating content.

3.2.1 | Motivations for participation

Seven contestants expressed their desire to improve society or help others feel supported as a key motivation for participating in the contest. Additionally, six AYA contestants were artistic and expressed wanting to develop creative materials or use their skills.

3.2.2 | Lessons learned from participation

All contestants reported learning something new about HIV, stigma and/or testing. A number of contestants reported learning that PLWH can live long and normal lives. Several contestants also mentioned learning about the ability for PLWH to give birth to children without HIV, indicating a persistent misperception in Kazakhstani society. Contestants also reported learning more about the challenges faced by PLWH, including children with HIV. Some contestants also reported using the knowledge and skills they gained from participating to design crowdsourcing projects to address other societal problems.

3.2.3 | Challenges creating content

Many contestants discussed the difficulty in creating content that could convey complex information using simple, non-stigmatizing language. Contestants wanted their work to have a positive impact and struggled to develop compelling mes-

saging. AYA also discussed the difficulty in sifting through stigmatizing information online to find reliable sources. Many AYA reported not being aware of HIV stigma themselves and needing to search for reliable information to become more informed. For some AYA, this included meeting with HIV specialists or other professionals. Contestants also reported some technological challenges in creating content. Although some AYA had extensive previous experience with video editing, audio and graphic software, other AYA had limited exposure to these types of tools and had to learn how to use them.

4 | DISCUSSION

The JasSpark Study used a citizen science approach to develop digital intervention materials to reduce HIV stigma and promote HIV self-testing among AYA. There is limited research on citizen science approaches to stigma reduction [28]. Most research aimed at HIV stigma reduction has used education-based, skills-building and/or counselling approaches with public health experts [6, 30, 31]. However, citizen science approaches have been used to address other issues facing AYA, such as school community wellbeing [32], barriers to physical activity [33], nutrition [34] and asthma [35].

The study serves as a useful model for designing inclusive methods to broaden public engagement in addressing stigma. Compared with other studies using crowdsourcing among diverse populations, we received a large number of submissions and a high percentage of high-quality submissions [18, 36], indicating high acceptability. Our findings indicate that crowdsourcing is a feasible citizen science approach to use among AYA in central Asia. A challenge in citizen science projects is finding engaged volunteers. While some projects have hundreds of volunteers, in some studies, less than 10.0% actively make contributions [37]. However, active participation among our AYA volunteers was high—greater than 90.0%, indicating citizen science approaches may be particularly well-suited for engaging AYA, particularly on topics they consider important. Of note, our AYA volunteers received no monetary compensation, only certificates of collaboration. Given that many AYA are applying for colleges or jobs and such certificates are valuable for their resumes, this may have been a motivating factor for their collaboration.

Motivations for participating in citizen science projects can vary, but often include reasons related to values (e.g. humanitarian concerns for others), understanding (e.g. opportunity for learning new skills/knowledge), social (e.g. opportunity for interacting with others), career (e.g. obtain career-related benefits) and protective (e.g. reduce guilt over being more fortunate than others) [37]. The majority of AYA citizen scientists in our study cited pro-social motivations. Many AYA had a strong desire to improve society and help youth or use their creative talents for good. Crowdsourcing provides AYA an opportunity to use their creative skills in a competitive forum, which may provide a way to engage them in an important topic they might not otherwise engage in.

Our study also highlighted the challenges associated with addressing stigma via citizen science approaches. Some crowdsourced materials developed by citizens could increase stigma, consistent with other literature [14]. Nearly, a third

of submissions contained stigmatizing content, indicating a need for vetting and refinement of community contributions. Approximately one-third of contestants revised submissions based on feedback, demonstrating a desire to learn. Open call submissions also served as a useful window to highlight where some sources of societal HIV stigma were stemming from—in this case, primarily around misperceptions and exaggerated fears about how HIV is transmitted. This is valuable for the design of future research studies and programmes to address HIV stigma in Kazakhstan and central Asia.

This study illustrates the promise of using a citizen science approach to develop HIV stigma reduction interventions. Strengths of this approach included strong participation from citizen scientists, including AYA; a large proportion of high-quality submissions; and the development of highly creative and innovative intervention content. We also implemented strong quality control procedures; all submissions in our study were reviewed by at least three people to determine whether the material included stigmatizing content.

However, there are some limitations. First, because this study was implemented in a real-world environment, we were not able to fully control all study processes (e.g. number of submissions, quality of submission content). Second, we did not ask for feedback from contestants who did not submit high-quality entries due to limited resources. Youth who were not finalists may have had different experiences and motivations for participating in the crowdsourcing contest. Third, approximately two-thirds of the total entries were from the younger age group (13–19 years) and the majority were in Russian. This suggests that if one wants to engage diverse groups of AYA, multiple open calls may need to be developed that engage young adults and those who speak only Kazakh. Individuals who speak only Kazakh tend to be predominately located in rural areas of Kazakhstan compared to individuals who are bilingual or speak only Russian, so contestants may have been more urban as well. Finally, each entry was reviewed by four different judges. Inter-rater agreement was low, suggesting the need for novel approaches to reduce the judging burden and have reliable ratings from a diverse community of judges. Further analyses of study results are ongoing [38] and will be reported in future papers.

5 | CONCLUSIONS

In summary, citizen science approaches hold great promise for addressing solutions for the increasingly complex health and social challenges facing communities today. Further work is needed to determine for which outcomes citizen science approaches are effective. In the often-challenging policy environments in EECA health systems, citizen science can be a tool for community change and make interventions more culturally relevant and innovative. Citizen science may also expand citizen knowledge of and trust in science and increase the inclusion of diverse communities. As investigators increasingly use citizen science approaches, it is important that details are shared across studies so that methods can be improved and best practices developed.

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COMPETING INTERESTS

The authors have no competing interests to declare.

AUTHORS' CONTRIBUTIONS

AD drafted the paper. All authors reviewed the paper and approved the final manuscript. AD, SLR, JDT, LN, KL, WT, OB, DG, VG, YS, SEL, AT, SP, GM and the JasSpark Study Team were involved in the study and instrument design. OB, DG, VG and GM collected the data. AD, YS, SEL, OB, DG and GM analysed the data. AD and GM obtained study funding.

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DATA AVAILABILITY STATEMENT

We plan by August 2024 to make JasSpark Study methods, data and results available to the public to the extent that governing data use agreements allow. The data-sharing plan will comply with the NIH Data Sharing Policy.

PERMISSION TO REPRODUCE MATERIAL FROM OTHER SOURCES

All contestants signed a multimedia release form providing permission to share their materials.

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SHORT REPORT

Mental health and cognition in relation to adherence to antiretroviral therapy among people living with HIV in Kazakhstan: a cross-sectional study

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Abstract

Introduction: There is a research gap in how mental health and cognition are associated with antiretroviral treatment (ART) adherence among people living with HIV (PLWH) in Kazakhstan.

Methods: We randomly selected and enrolled 230 PLWH from the Almaty City AIDS Center registry (June–November 2019) into a cross-sectional study. We examined associations between self-reported ART adherence for the last 1 and 2 weeks; the Adherence Self-Efficacy Scale (ASES) and symptoms of depression (Patient Health Questionnaire-9 [PHQ-9]), anxiety (Generalized Anxiety Disorder tool [GAD-7]), post-traumatic stress disorder (PTSD Checklist [PTSD]); cognitive function (PROMIS v2.0 Adult Cognitive Function 8a short form) and forgetfulness (Forgetfulness Assessment Inventory). We used cut points of ≥ 5 for at least mild and ≥ 10 for at least moderate symptom severity for PHQ-9 and GAD-7 and of ≥ 44 for PTSD. Logistic and linear regression analyses were used.

Results: Participants' median age was 40.0 (IQR: 34–47) with 40.9% ($n = 94$) of females in the sample. Those who missed at least one pill for the last 2 weeks had higher odds of reporting at least mild depression (aOR = 3.34, 95% CI: 1.22–9.11, $p < 0.05$); mild anxiety (aOR = 3.27, 95% CI: 1.20–8.92, $p < 0.05$); and PTSD (aOR = 4.04, 95% CI: 1.15–14.21, $p < 0.05$) symptoms. Participants who missed at least one pill for the last week had higher odds of at least mild depression (aOR = 7.74, 95% CI: 1.31–45.7, $p < 0.05$), moderate anxiety (aOR = 21.33, 95% CI: 3.24–140.33, $p < 0.005$) and PTSD (aOR = 13.81, 95% CI: 2.36–80.84, $p < 0.005$) symptoms. Participants with better cognitive function had lower odds of non-adherence over the last week (aOR = 0.88, 95% CI: 0.81–0.96, $p < 0.005$) and higher ASES scores ($\beta = 0.26$, 95% CI: 0.13–0.40, $p < 0.005$). Poor memory was associated with higher odds of non-adherence over the last week (aOR = 4.64, 95% CI: 1.76–12.24, $p < 0.005$) and lower ASES score ($\beta = -0.31$, 95% CI: -0.45 to 0.16 , $p < 0.005$). Those who had at least mild depression ($\beta = -0.21$, 95% CI: -0.35 to -0.07 , $p < 0.005$); moderate anxiety ($\beta = -0.21$, 95% CI: -0.34 to -0.07 , $p < 0.005$) and PTSD ($\beta = -0.19$, 95% CI: -0.33 to -0.05 , $p < 0.005$) symptoms had lower ASES scores.

Conclusions: Depression, anxiety and PTSD symptoms, poorer cognition, and forgetfulness were associated with poorer ART adherence and worse adherence self-efficacy. It is crucial to assess and treat mental illness and provide support for PLWH with worsened cognition to enhance ART adherence.

Keywords: HIV; ART adherence; depression; anxiety; cognition; forgetfulness

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1 | INTRODUCTION

Eastern Europe and central Asia (EECA), including Kazakhstan [1], is the only region with a rising HIV incidence, with an estimated 33,000 people living with HIV (PLWH). Of these, 80% knew their HIV status, 64% received antiretroviral treatment (ART) and 55% had a viral load of <1000 copies/ml [2].

In 2019, an estimated 13% of the global population was living with a mood disorder (depression 29%, anxiety 31%), and 82% in low- and middle-income countries [3]. Among PLWH globally, the prevalence of mental health disorders is high [4–20]. Prevalence of depression among PLWH from high-income countries varied between 5% and 20% [9, 21, 22]. One study reported that ~10% of PLWH had

symptoms of depression in Almaty, Kazakhstan [23]. Multiple studies revealed associations between mental health disorders and high viral load, which are often associated with poor adherence [7, 8, 24–30]. HIV affects cognitive function and mental health [31–37]. Also, some ART regimens may have neuropsychiatric side effects [38].

Published literature indicates that ART adherence is associated with mental health and cognitive function among PLWH globally. However, there is limited data on associations of ART adherence and ART self-efficacy with mental health symptoms and cognition among PLWH in Kazakhstan. We hypothesized that symptoms of depression, anxiety and post-traumatic stress disorder (PTSD) as well as poorer cognition, are associated with poorer ART adherence and lower ART self-efficacy. In this cross-sectional study, we examined the association of ART adherence and ART self-efficacy with depression symptoms, anxiety symptoms, clinically relevant PTSD and cognitive function among PLWH in Almaty, Kazakhstan.

2 | METHODS

This cross-sectional study took place in Almaty, Kazakhstan. In Kazakhstan, all HIV-related services (testing, treatment and prevention) are provided by AIDS centres. The Almaty AIDS City Center is the only healthcare facility that provides HIV-related services for PLWH in Almaty. Eligibility criteria were: (1) 18 years old or older; and (2) prescribed ART for at least 6 months. PLWH were excluded if they (1) showed evidence of very severe psychiatric or cognitive impairment or (2) were not fluent in Russian. We randomly selected 246 participants from the Almaty AIDS City Center roster and 230 were successfully enrolled in the study between June and November 2019. Each participant signed a consent form and received compensation (~USD\$10) for a 90-minute computerized self-assisted interview. The interview was monitored by a trained psychologist, who also provided a consultation and referral for treatment. A nurse extracted clinical data from the medical records of participants. We were unable to utilize CD4⁺ cell count and HIV viral load because laboratory tests were collected across wide time intervals (every 6 months), which did not align with survey dates. All data were collected using surveys.

2.1 | Ethical approvals

The study obtained ethical approvals from the Al-Farabi Kazakh National University Ethics Committee and the Columbia University Institutional Review Board.

2.2 | Measures

2.2.1 | Dependent variables

Self-reported ART adherence. Self-reported ART adherence was determined by answering the question: “When was the last time you missed taking any of your antiretroviral medications?” Response options were: “last 3 days,” “within the past week,” “1–2 weeks ago,” “2–4 weeks ago,”

“3 months ago,” “more than 3 months ago,” “never skip medications.”

Adults who reported (1) missing at least one pill in the last week and (2) missing at least one pill in the last 2 weeks were defined as two categories of ART non-adherent participants, while those who did not miss any pills in these time periods were defined as ART adherent.

Adherence self-efficacy. The 12-item Adherence Self-Efficacy Scale (ASES) was used to assess PLWH's adherence self-efficacy [39]. Responses range from 1 (cannot do it at all) to 10 (certainly can do it). Item scores were averaged for each respondent, with higher scores indicating higher adherence self-efficacy [39]. The overall score ranged from 0 to 120. Cronbach's alpha in our sample was $\alpha = 0.97$.

Independent variables. Socio-demographic variables included age, gender, employment status, marital status, ethnicity, history of ever being diagnosed with infectious diseases, self-reported history of ever being diagnosed with any mental illness and education level. Substance use variables included injection drug use ever in a lifetime (yes/no) and hazardous alcohol drinking, assessed by the Alcohol Use Disorders Identification Test (AUDIT). A score of ≥ 8 is considered hazardous drinking [35]. The Cronbach's alpha in our sample was $\alpha = 0.879505$.

Mental health measures. To evaluate depressive symptoms, we used the Patient Health Questionnaire-9 (PHQ-9) [40], with a total score range of 0–27. Scores of 0–4, 5–9, 10–14, 15–19 and 20–27 represent cut points for no, mild, moderate, moderately severe and severe depression, respectively. We used cut points of ≥ 5 for at least mild and ≥ 10 for at least moderate depression symptom severity [41]. The Cronbach's alpha in our sample was $\alpha = 0.90$.

The Generalized Anxiety Disorder (GAD-7) instrument was used [42], with a score range of 0–21. Scores of 0–4, 5–9, 10–14 and 15–21 represent ranges for minimal, mild, moderate and severe anxiety, respectively. We used cut points of ≥ 5 for at least mild and ≥ 10 for at least moderate anxiety symptom severity. The Cronbach's alpha in our sample was $\alpha = 0.92$.

The PTSD Checklist (PCL) was used to measure PTSD: a 17-item self-report questionnaire (score range 17–74) [43, 44]. A score of ≥ 44 is considered to be clinically relevant PTSD. The Cronbach's alpha in our sample was $\alpha = 0.96$.

2.3 | Cognitive measures

PROMIS v2.0 Adult Cognitive Function 8a short form (8-item) was used to assess cognitive function [45]. The PROMIS v2.0 assesses the frequency of cognitive difficulties experienced in the past 7 days based on self-report. Lower raw scores on the PROMIS v2.0 indicate greater subjective cognitive difficulty [46]. The total raw score ranges from 8 to 40. The Cronbach's alpha in our sample was $\alpha = 0.96$. The 16-item Forgetfulness Assessment Inventory was used to assess subjective memory over the past 4 weeks. A higher score corresponds to more forgetfulness or poorer memory [47]. Responses were recorded on a 5-point Likert scale. The overall score ranges from 0 to 5 [47]. Cronbach's alpha in our sample was $\alpha = 0.95$.

2.4 | Data analysis

Descriptive statistics were used to summarize participant characteristics for history of mental illness and socio-demographic variables. The median and interquartile range (IQR) for continuous variables were calculated for the total sample and by the self-reported history of ever being diagnosed with any mental illness.

Percentages of participants who screened positive for mental health symptoms were calculated based on clinically relevant cut-points of the PHQ-9 score for depression symptoms, including at least mild (score ≥ 5) and at least moderate symptoms (score ≥ 10); cut-points of the GAD-7 screening instrument, for at least mild (score ≥ 5) and moderate (score ≥ 10) anxiety symptoms; and cut-point of PCL (score ≥ 44) for clinically relevant PTSD.

We employed multivariable regression analyses to address two self-reported dependent variables: ART adherence and ASES score. For each primary independent variable: clinically relevant depression symptoms, anxiety symptoms, clinically relevant PTSD, cognitive function and forgetfulness, we used logistic regression analyses to calculate crude odds ratios (OR) and 95% confidence intervals (95% CI) to evaluate associations of self-reported ART non-adherence: missed at least one pill in the last 2 weeks and missed at least one pill in the last week separately. For each primary independent variable, we conducted multivariable logistic regression analyses, adjusting for age, sex, education, employment, injection drug use and hazardous drinking.

The second dependent variable was the continuous ASES score. Linear regression analyses were used to calculate crude standardized regression coefficients (β) with 95% CI to predict the ASES score by each primary independent variable. Then, multivariable standardized regression coefficients (β) with 95% CI were calculated separately for each independent variable adjusted for age, gender, education, employment, injection drug use and hazardous drinking. All analyses were conducted using SAS statistical software version 9.4.

3 | RESULTS

3.1 | Sample characteristics

Table 1 shows the demographic, clinical and other characteristics, including adherence to ART, ASES scale, mental health symptoms, cognitive function score and forgetfulness score of the sample stratified by self-reported mental health illness ever diagnosed in their lifetime.

3.2 | Associations of ART adherence with depression symptoms, anxiety symptoms, clinically relevant PTSD and cognitive function

Multivariable logistic regression analyses showed that mental health symptoms were associated with a higher probability of non-adherence to ART (Table 2). Those who missed at least one pill in the last 2 weeks had higher odds of reporting mild (aOR = 3.34, 95% CI: 1.22–9.11, $p < 0.05$) or moderate (aOR = 4.38, 95% CI: 1.36–14.15, $p < 0.05$) depression symptoms; mild (aOR = 3.27, 95% CI: 1.20–8.92, $p < 0.05$) or moderate

(aOR = 8.61, 95% CI: 2.32–31.87, $p < 0.005$) anxiety symptoms; and PTSD symptoms (aOR = 4.04, 95% CI: 1.15–14.21, $p < 0.05$) (Table 2).

Participants who missed at least one pill in the last week had higher odds of reporting mild (aOR = 7.74, 95% CI: 1.31–45.7, $p < 0.05$) or moderate (aOR = 10.06, 95% CI: 1.81–55.76, $p < 0.01$) depression symptoms; moderate (aOR = 21.33, 95% CI: 3.24–140.33, $p < 0.005$) anxiety symptoms and symptoms of PTSD (aOR = 13.81, 95% CI: 2.36–80.84, $p < 0.005$).

Participants with better cognitive function had lower odds of non-adherence in the last week (aOR = 0.88, 95% CI: 0.81–0.96, $p < 0.005$). Having more forgetfulness was associated with higher odds of non-adherence in the last week (aOR = 4.64, 95% CI: 1.76–12.24, $p < 0.005$) (Table 2).

3.3 | Association of ART self-efficacy with depression symptoms, anxiety symptoms, clinically relevant PTSD and cognitive function among PLWH in Almaty, Kazakhstan

Multivariable linear regression analyses showed that mental health symptoms were associated with lower adherence self-efficacy. Those who had moderate depressive symptoms ($\beta = -0.15$, 95% CI: -0.30 to -0.01 , $p < 0.05$), mild anxiety symptoms ($\beta = -0.21$, 95% CI: -0.35 to -0.07 , $p < 0.005$) and moderate anxiety symptoms ($\beta = -0.21$, 95% CI: -0.34 , -0.07 , $p < 0.005$) and higher number of PTSD symptoms ($\beta = -0.19$, 95% CI: -0.33 to -0.05 , $p < 0.005$) had lower adherence self-efficacy scores (Table 3).

Participants with better cognitive function had higher ASES scores ($\beta = 0.26$, 95% CI: 0.13–0.40, $p < 0.005$). A higher forgetfulness score, denoting poorer memory, was associated with a lower ASES score ($\beta = -0.31$, 95% CI: -0.45 to -0.16 , $p < 0.005$) (Table 3).

4 | DISCUSSION

This study addresses a gap in research on how mental health and cognitive function impact adherence to ART among PLWH in Kazakhstan. Our findings suggest that depression, anxiety, PTSD symptoms and worsened cognitive function are associated with poorer ART adherence and lower adherence self-efficacy, which is consistent with previous research on PLWH in other countries [7, 8, 24–26, 48–53].

There are multiple studies demonstrating that HIV is linked to an increased likelihood of cognitive impairment due to the underlying pathophysiology of HIV [31–35, 50, 54]. On the other hand, long-term exposure to ART medications can be associated with neurocognitive impairment [55, 56]. The neurotoxic and neuropsychiatric impacts stemming from both the ART and the HIV infection itself necessitate a more comprehensive grasp of the pathological, pharmacological and behavioural mechanisms involved into the worsening of the cognitive function of PLWH [57–60].

This study has several limitations. First, as a cross-sectional study, we cannot determine the causality of relationships between mental health, cognitive function and ART adherence. Second, due to social desirability bias, participants may have overreported adherence to ART and overrated cognitive

Table 1. Socio-demographic characteristics of the study sample stratified by self-reported mental health diagnosis ever in lifetime

Characteristic	Overall, N = 230 (100%)	Mental health diagnosis ever ^a , n = 77 (33.5%)	No mental health diagnosis ever, n = 153 (66.5%)	p-value
Age (mean [SD])	41.9 (10.3)	42.5 (11.3)	41.5 (10.2)	0.532
Sex				0.032
Male	136 (59.1)	38 (49.4)	98 (64.1)	
Female	94 (40.9)	39 (50.7)	55 (35.9)	
Ethnicity				0.674
Kazakh	72 (31.3)	22 (28.6)	50 (32.7)	
Russian	114 (49.6)	73 (53.3)	41 (47.7)	
Other	44 (19.6)	14 (18.2)	30 (19.6)	
Completed high education (bachelor/graduate degree)	133 (57.8)	33 (42.9)	100 (65.4)	0.001
Full-time employment (yes/no)	180 (78.3)	60 (77.9)	120 (78.4)	0.843
Marital status				
Single (never married, divorced, separated, widowed)	114 (49.6)	37 (48.1)	77 (50.3)	0.799
Married	116 (50.4)	40 (51.9)	76 (49.7)	0.799
Injection drug use (ever)	57 (24.8)	23 (29.9)	34 (22.2)	0.205
Hazardous alcohol drinking (AUDIT score ≥ 8)	38 (16.5)	16 (20.8)	22 (14.4)	0.217
Infectious disease history (ever in life history)	N (%)	N (%)	N (%)	p
HCV (ever had positive EIA),	74 (32.2)	27 (35.1)	47 (30.7)	0.506
HBV (ever had positive EIA)	8 (3.5)	6 (7.8)	2 (1.3)	0.018 ^a
Syphilis (ever serologically positive)	29 (12.7)	11 (14.3)	18 (11.8)	0.599
Tuberculosis (ever diagnosed)	41 (17.8)	18 (23.4)	23 (15.0)	0.119
Toxoplasma (ever had positive EIA)	11 (5.0)	3 (4.0)	8 (5.5)	0.753
Cytomegalovirus (ever had positive EIA)	10 (4.4)	3 (3.9)	7 (4.7)	0.262
At least mild symptoms* of depression	66 (28.7)	31 (40.3)	35 (22.9)	0.0060
At least moderate symptoms** of depression	22 (9.6)	11 (14.3)	11 (7.2)	0.0842
At least mild symptoms* of anxiety	74 (32.2)	29 (37.7)	45 (29.4)	0.2062
At least moderate symptoms** of anxiety	15 (6.5)	9 (11.7)	6 (3.9)	0.0244
At least mild symptoms* of depression and anxiety	46 (20.0)	20 (26.0)	26 (17.0)	0.1081
At least moderate symptoms** of depression and anxiety	13 (5.7)	7 (9.1)	6 (3.9)	0.1330 ^a
Symptoms of PTSD	17 (7.4)	10 (13.0)	7 (4.6)	0.0214
Self-reported adherence (missed at least one pill of medication)				
Within the last month	42 (18.3)	12 (15.6)	30 (19.6)	0.456
Within the last 2 weeks	22 (9.6)	6 (7.8)	16 (10.5)	0.517
Within the last week	7 (3.0)	3 (3.9)	4 (2.6)	0.689 ^a
Within the last 3 days	4 (1.7)	2 (1.3)	2 (2.6)	0.603 ^a
	Median (IQR)	Median (IQR)	Median (IQR)	p
Cognitive function (raw score)	40 (34–40)	40 (32–40)	40 (35–40)	0.194
Forgetfulness score	1.44 (1.13–2.06)	1.56 (1.19–2.13)	1.44 (1.0–2.06)	0.094 ^b
ASES (raw score)	120 (112–120)	120 (117–120)	120 (110–120)	0.218 ^b
GAD-7 (raw score)	2.0 (0–5)	3 (1–6)	2 (0–5)	0.009

(Continued)

Table 1. Continued

Characteristic	Overall, N = 230 (100%)	Mental health diagnosis ever ^a , n = 77 (33.5%)	No mental health diagnosis ever, n = 153 (66.5%)	p-value
PHQ-9 (raw score)	2.0 (1–6)	3 (1–7)	2 (0–4)	0.004

Abbreviations: ASES, adherence self-efficacy scale; AUDIT, alcohol use disorders identification test; EIA, enzyme immunoassay; GAD-7, generalized anxiety disorder-7; HBV, hepatitis B virus; HCV, hepatitis C virus; IQR, interquartile range; PHQ-9, patient health questionnaire; PTSD, post-traumatic stress disorder; SD, standard deviation.

^aFisher.

^bWilcoxon.

^cDiagnosed with any of the following conditions: depression, anxiety, bipolar disorder, schizophrenia or any other mental health condition.

*For PHQ-9 and GAD-7: at least mild symptoms (score ≥ 5).

**For PHQ-9 and GAD-7: at least moderate symptoms (score ≥ 10).

Table 2. Unadjusted and adjusted logistic regression for participants who missed at least one pill in the last 2 weeks and in the last week symptoms of mental health symptoms, cognitive function and forgetfulness scores

	Missed at least one pill in the last 2 weeks		Missed at least one pill in the last week	
	Unadjusted OR (95% CI)	Multivariable adjusted OR (95% CI)	Unadjusted OR (95% CI)	Multivariable adjusted OR (95% CI)
Mental health symptoms				
Depression symptoms (at least mild, ≥ 5)	4.23 (1.71–10.45)*	3.34 (1.22–9.11)*	6.64 (1.26–35.13)*	7.74 (1.31–45.7)*
Depression symptoms (at least moderate, ≥ 10)	4.50 (1.55–13.09)*	4.38 (1.36–14.15)*	8.05 (1.68–38.67)**	10.05 (1.81–55.76)**
Anxiety symptoms (at least mild, ≥ 5)	3.48 (1.41–8.57)*	3.27 (1.20–8.92)*	2.92 (0.64–13.37)	4.53 (0.80–25.64)
Anxiety symptoms (at least moderate, ≥ 10)	8.29 (2.62–26.24)***	8.61(2.32–31.87)***	13.19 (2.65–65.71)**	21.33 (3.24–140.33)***
PTSD (≥ 44)	4.80 (1.51–15.25)*	4.04 (1.15–14.21)*	11.20 (2.28–55.00)**	13.81 (2.36–80.84)***
Depression and anxiety (at least moderate symptoms, ≥ 10)	10.77 (3.23–35.87)***	11.94 (2.95–48.30)***	15.98 (3.14–81.19)***	43.22 (5.28–353.54)***
Depression and anxiety (at least mild symptoms, ≥ 5)	3.98 (1.60–9.92)*	3.43 (1.21–9.69)*	5.75 (1.24–26.65)*	8.97 (1.61–49.91)*
Cognitive function raw score	0.96 (0.90–1.01)	0.97 (0.91–1.03)	0.89 (0.83–0.96)**	0.88 (0.81–0.96)***
Forgetfulness raw score	1.90 (1.13–3.19)**	1.60 (0.90–2.85)	3.48 (1.55–7.81)**	4.64 (1.76–12.24)***

Abbreviation: PTSD, post-traumatic stress disorder.

*** $p < 0.005$; ** $p < 0.01$; * $p < 0.05$.

function and may have provided socially acceptable answers [61]. Third, as noted above, we did not have concurrent data on CD4⁺ cell count and HIV viral load. In addition, while T-scores for PROMISv2, our cognitive function assessment, exist for the US general population, we did not convert our raw scores to T-scores for these analyses since they may not be representative of PLWH in Kazakhstan. PROMISv2 T-scores do not exist for the Kazakh population [62]. However, this study had several strengths that address some limitations in prior research including the use of a random sample from a roster of PLWH patients at the largest city AIDS Center, high participation rates and the use of validated scales of mental health and cognitive function with good reliability.

Research showed that PLWH can benefit from a wide range of mental health interventions [63]. These four models are suggested to be promising strategies for delivering efficient and effective mental healthcare in resource-constrained settings: task shifting, stepped care, trans-diagnostic approaches and technology-based interventions [63, 64]. Routine screenings for mental health issues [65, 66] integrated into the HIV care continuum with mental health counselling shifting from specialized to non-specialized health workers or trained lay persons are promising intervention approaches [67–69]. Clinicians have to be able to screen for mental health disorders and access cognitive function to refer for treatments [63] and provide support for patients with worsened cogni-

Table 3. Unadjusted and adjusted linear regression for ASES score of participants and symptoms of mental health symptoms, cognitive function and forgetfulness scores

Mental health symptoms	ASES score	
	Crude standardized β (95% CI)	Multivariable standardized β (95% CI)
Depression symptoms (at least mild, ≥ 5)	-0.14 (-0.27 to -0.00)*	-0.14 (-0.28 to 0.01)
Depression symptoms (at least moderate, ≥ 10)	-0.13 (-0.28 to -0.001)*	-0.15 (-0.30 to -0.01)*
Anxiety symptoms (at least mild, ≥ 5)	-0.21 (-0.35 to -0.08)***	-0.21 (-0.35 to -0.07)***
Anxiety symptoms (at least moderate, ≥ 10)	-0.19 (-0.31 to -0.06)***	-0.21 (-0.34 to -0.07)***
PTSD	-0.18 (-0.31 to -0.05)**	-0.19 (-0.33 to -0.05)**
Depression and anxiety (moderate symptoms)	-0.14 (-0.27 to -0.01)*	-0.16 (-0.29 to -0.02)*
Depression and anxiety (mild symptoms)	0.20 (-0.33 to -0.07)***	-0.20 (-0.35 to -0.06)**
Depression and PTSD	-0.17 (-0.29 to -0.03)*	-0.18 (-0.31 to -0.04)*
Anxiety and PTSD	-0.12 (-0.24 to 0.02)	-0.12 (-0.25 to 0.01)
Cognitive function score	0.26 (0.13–0.39)***	0.26 (0.13–0.40)***
Forgetfulness score	-0.27 (-0.40 to -0.14)***	-0.31 (-0.45 to -0.16)***

Abbreviations: ASES, adherence self-efficacy scale; PTSD, post-traumatic stress disorder.

*** $p < .005$; ** $p < .01$; * $p < .05$.

tive function to improve their ART adherence [22, 70–76]. Technology-based approaches including digitalized interventions that can be delivered via applications on smartphone or other devices can be effective way to support PLWH with mental illness or/and worsened cognition [77, 78].

5 | CONCLUSIONS

The findings emphasize the vital importance of incorporating mental health and cognitive function assessments into HIV treatment programmes. This approach is essential due to the observed links between mental health issues and diminished cognitive abilities, including forgetfulness, and their correlation with reduced adherence to ART and lower self-efficacy in treatment adherence. Strengthening mental health support and focusing on the cognitive function within these programmes can significantly enhance the adherence and overall wellbeing of PLWH.

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COMPETING INTERESTS

The authors declare no competing interests.

AUTHORS' CONTRIBUTIONS

GM and AD collaborated on drafting the manuscript. JD, NE-B, LG, DG, SLR, ANP, AT and SP contributed to revisions of manuscript drafts. GM, JD, AD and ANP contributed to outlining the research objectives, sampling design and data analysis. GM and AD contributed to data analysis. JD, DG, LG, NE, AT, SP, ZN, ANP and AYD contributed substantially to the conception and design of the work and interpretation of results. AYD contributed to data collection. All authors had final approval

of the version to be published and agreed to be accountable for all aspects of the work.

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DATA AVAILABILITY STATEMENT

Data are available on request from the authors.

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