**Abstract.** Eastern Europe and Central Asia (EECA) is a region with the fastest growing HIV epidemic in the world. Trans people are one of the key population groups susceptible to HIV, according to the UNAIDS. However, in 8 out of 12 EECA countries, they are not recognized as a key group by the state. This article explores the attitudes of activists toward the separation of trans people from other key groups, especially men having sex with men (MSM). The second research question concerns activists’ understanding of the limitations of qualitative research (with a particular focus on population size estimations) widespread in HIV programming. In addition, the article highlights the main areas of HIV-related trans activism, the use of HIV as a vehicle to promote access to gender-affirming services, and barriers faced by activists.

**Keywords:** transgender, key populations, social movements, HIV, post-Soviet

**Transgender HIV activism in Eastern Europe and Central Asia**

## Introduction

The point of departure for this article was an anonymous reviewer's comment on my article on transgender health, which read: “I would suggest shifting focus AWAY from HIV. . . the over-emphasis on HIV reinforces the negative association and media stigmatisation of the LGBTQI+ community in the 1980s.” Apparently, the reviewer was mainly referring to the US context. However, for me as a researcher focusing on transgender health (including HIV) in Eastern Europe and Central Asia (EECA)[[1]](#footnote-2) this comment felt too far from the realities and needs of trans movements in the region. Raising awareness of the HIV epidemics in trans communities and advocacy for the recognition of trans people as a separate key population group not conflated with men having sex with men (MSM) and sex workers are major goals for trans activists in EECA. Thus, the main goal of this article was to provide insight into HIV-related trans activism in EECA, a region with the fastest growing HIV epidemic in the world (UNAIDS, 2023), which, nevertheless, remains understudied in international literature, especially in the context of trans issues. The specific research question was: “What are the attitudes of trans communities and activists toward the recognition of trans people as a key group vulnerable to HIV?”

Quantitative research is the mainstay of HIV programs throughout the world. Trans people in EECA, who had largely been ignored by non-governmental organizations (NGOs) and researchers in previous years, are currently being actively researched on topics related to HIV, with the goal of establishing population size and HIV prevalence estimates. Being one of these researchers, I am critical of the positivist philosophy underpinning these projects, which aim to categorize and quantify individuals whose identities and belongings are inherently unstable and fluctuating. Thus, my second research question was: “What do activists think about the reliability and utility of quantitative studies in the HIV sphere?”

## Background

### HIV and trans issues in EECA

The first case of HIV in the world is dated to 1959 (Zhu et al., 1998). Due to its relative isolation from the rest of the world (such as the requirement for exit visas for Soviet citizens wishing to go abroad), the USSR had an almost three-decade lag before the first Soviet patient zero with AIDS was officially identified in 1987. This patient contracted the virus on a work trip to Eastern Africa, where he had homosexual contacts with local residents in 1981 (Medvedev, 1990). However, even before that time, Soviet doctors started raising alarms about AIDS, citing foreign sources, with the first newspaper article published in 1983 (Alexander, 2023). The official response first varied from denying the problem to blaming Western degrading social mores, which tolerated promiscuity and homosexuality (Alexander, 2023; Feshbach, 2006). In 1987, measures were taken to identify HIV in the population, with a special focus on at-risk groups, including homosexuals, drug users, and sex workers. In the same year, transmission of HIV was criminalized (Alexander, 2023).

Post-Soviet countries largely followed this punitive approach. As of 2023, all EECA countries, except Kazakhstan, criminalize HIV transmission. On the other hand, the democratization and opening of the newly established countries after the USSR’s collapse in 1991 enabled the development of NGOs working on HIV issues and LGBT rights. Their financial resources came primarily from abroad, especially from the Global Fund to Fight AIDS, Tuberculosis and Malaria (hereinafter: Global Fund). However, the extent to which EECA countries wish to succumb to international influence depends on their geopolitical relationships with the West. Russia, the region’s country with the higest number of registered AIDS cases, tends to downplay the significance of the problem and emphasize the importance of moral values in fighting the epidemic (Yasaveev, 2020). In 2021, Russia’s Ministry of Foreign Affairs criticized the new Global AIDS Strategy for 2021–2026 for “the expansion of the UNAIDS mandate beyond medico-social activities,” as well as the lack of measures on promoting healthy lifestyle and family values (The Ministry..., 2021), thus dismissing the link between AIDS outcomes and stigma, discrimination, criminalization, as well as human rights outlined in the new Strategy. Another country denying the AIDS epidemic is Turkmenistan, where doctors are prohibited from officially diagnosing patients with AIDS; as a result, only two AIDS cases have been reported (Turkmen News and Yoursky, 2019). Other EECA countries are all along the way between denying the problem and cooperating with civil society to provide inclusive HIV prevention and treatment.

When it comes to trans people, the first Soviet accounts of gender-affirming care were recorded in the late 1960s. Care was provided primarily in Moscow and later in Rostov-on-Don and Saint-Petersburg by enthusiastic Soviet doctors (Kirey-Sitnikova, 2022). However, because of the silencing of everything related to sexuality, trans issues were not discussed openly. Only in the late 1980s, did the reforms initiated by Mikhail Gorbachev permit increasing freedom of the press. Despite the growth of trans visibility in the 1990s, there is no evidence that the media linked HIV and “transsexualism,” which was largely perceived as a medical (as opposed to moral) problem. Unlike Western countries, trans people were not forming geographically proximate communities although they could maintain communication via regular post (Lefevr and Eroshenko, 2023). Trans people were also largely excluded from the emerging LGB(T) activism until the mid-2000s to mid-2010s (depending on the country). During the past decade, many independent trans-led groups have emerged. Their modes of activism and areas of work vary to include advocacy, street protests, and blogging to simplify legal gender recognition, improve access to gender-affirming healthcare, and fight societal transphobia (Kirey-Sitnikova and Kirey, 2019). The importance of HIV in trans activists’ agendas varies depending on the country and the beneficiaries they serve. In three countries of the region (Georgia, Kyrgyzstan, Moldova), trans activists were successful in making the state recognize them as a separate key population group; in Armenia, trans women specifically are recognized as an at-risk group (Eurasian Coalition..., 2023). Similar to other parts of the world, trans people in EECA underprioritize HIV prevention and treatment in favor of more acute needs such as legal gender recognition, gender-affirming healthcare, and employment (Kirey-Sitnikova, 2023).

### The positivist philosophy underpinning HIV-related trans research and activism

The HIV care cascade (also termed “continuum”) is a tool widely used to identify gaps in HIV care. It provides data such as the number of people living with HIV (PLWH), the percentages of PLWH who know their HIV status, who are linked to care, who receive antiretroviral therapy (ARVT), and whose viral load is suppressed (the actual composition of the cascade might vary based on the purpose) (Kay, 2016). According to the UNAIDS’s Fast Track Strategy, to end the HIV epidemic by 2030, indicators “95–95–95” must be achieved by 2025, meaning that 95% PLWH know their status, 95% of those receive ARVT, and 95% of those receiving ARVT have their viral load suppressed (Frescura 2022). To calculate these percentages, one must start with the very first number — the population size, in our case, the number of trans people in a country.

Trans population estimates in EECA give results in the range between 0.02% in Ukraine (Kasianczuk and Trofymenko, 2020) and 0.06% in Armenia (Davtyan et al., 2021) — the latter figure is for trans women as compared to all women. International data give an even wider range — between 0.00017% and 0.599% (Meier and Labuski, 2013). The reasons for such a discrepancy are that trans people are a hard-to-reach population and there is no consensus on the boundaries of the “trans” category (Ibid.). While the former problem can be overcome by cultivating trust between the researchers and researched or by providing financial incentives, the latter appears to be an intractable issue. Not a stable biological reality, trans identities fluctuate and develop, with the growing number of ways to describe oneself, and the boundary between cis and trans being sometimes blurred. I heard about MSMs from Uzbekistan, who go to Russia to earn money as sex workers and undergo mammoplasty to be perceived as trans women, but later they remove breast implants and return to their home country to live as men again. There are individuals who detransition for both internal (related to gender identity) and external (discrimination, medical, legal, or financial issues) reasons (Turban 2021); some of them later retransition again. Some individuals do not distinguish between their gender identity and sexual orientation. In certain cultural contexts, traditional non-binary gender roles do not fit into the clearly-defined Western categories “MSM” and “trans” (Parker 2016).

Further complications arise when trying to classify trans respondents into subgroups such as trans women, trans men, and non-binary people. For example, recently, an NGO I work for wanted to know whether differences in HIV prevalence between trans men and non-binary people were statistically significant. In my research, I prefer the two-question method (Tate 2013), meaning that sex assigned at birth and gender identity are collected separately. Not wishing to force my respondents to fit themselves into pre-existing categories, I use an open question about gender identity. There are not a few respondents who write “non-binary trans man” or “queer trans girl,” which is not a good answer if you want to calculate odds ratios between trans men and non-binary people. I have my own rules for these cases: respondents who list “non-binary,” “queer,” “genderfluid,” or “agender” among their identities are classified as non-binary, and then the statistics are calculated. But would these respondents classify themselves in the same way if forced to choose between categories? Are these categories relevant to them at all? In the case of intersex respondents, the question about sex assigned at birth can also be misleading.

I think a lot about these issues not just as a researcher but also as a trans person without a clear identity. I do not identify as trans despite “technically” being trans (having undergone legal gender recognition and gender-affirming medical procedures). I detransitioned and retransitioned three times for various reasons. Sometimes I am not sure how I would answer my own survey questions. However, my clients from among NGOs want numbers on clearly defined key population groups.

## Positionality and methods

As a trans person, I have been involved in trans activism in Russia since 2010, moving to the regional level (EECA) in 2013. Later, I moved to research in the broad area of transgender studies. After graduating with a Master’s degree in Public Health, I started working as a research consultant for NGOs on transgender health. Being HIV-negative with very low risk of contracting HIV, I have never been involved in the HIV sphere as an activist. However, one of my clients heavily focuses on HIV research, and this is how I became involved. This means that I have a first-hand experience in trans activism in EECA, but my understanding of HIV activism comes from my experience as a researcher, not an activist.

The interview questions were developed on the basis of my experience of working with HIV activists in EECA. Convenience sampling was used, with potential respondents (one per country) identified on the basis of my previous connections and my own judgment of the respondents’ expert status on trans and HIV issues within that country. In three cases, activists referred me to a different respondent, who, in their opinion, had deeper knowledge of the issues under investigation. Nothing is known about trans or HIV activism in Turkmenistan, so this country was excluded. The respondent from Belarus has not answered the interview questions by the deadline of this submission (if she eventually answers, I will include quotes before the next stage of peer-reviewing). In addition, two regional-level experts working in international NGOs were questioned to understand the general picture. The data were collected in September-October 2023. Online interviewing was the preferred method, although in one case a written interview was used at the request of the respondent, whereas in another case the respondent answered via voice messages. Oral informed consent was obtained at the start of interviews. Audio recordings were manually transcribed. Two interviews (Armenia, Georgia) were conducted in English, while the rest were conducted in Russian. Russian-language quotes were translated into English by the author. A grounded theory approach was used to identify codes and further combine them into broader themes. Quotes were used to illustrate the main findings. The respondents had different preferences regarding being named or anonymized. For consistency, all quotes were anonymized. Since each country was represented by one activist, country codes according to ISO 3166-1 alpha-3 were used for identification (for example, UZB for the respondent from Uzbekistan). The two regional-level experts were named REG1 and REG2, respectively.

## Results

The average age of the participants was 35.5 (range 26 to 50). The following gender identities were reported: respondents from Kazakhstan, Kyrgyzstan, Tajikistan, and one regional-level expert — trans men; Ukraine — trans masculine person; Armenia and one regional-level expert — non-binary; Armenia — gender-fluid; Russia — trans woman; Azerbaijan, Moldova, and Uzbekistan — cisgender men. The results will be reported first according to the four general areas of HIV-related trans activism in EECA, which include: providing direct services, advocacy, research, and educating doctors. Later sections will be devoted to three cross-cutting topics: How can fluid and complex identities be fitted into categories? Why is HIV used to promote other issues? What challenges do activists face in their work?

### 1. Direct services

Provision of direct HIV prevention and treatment services to trans people is the basic activity performed in every country under consideration. Prevention services included in the basic package were condoms, lubricants, HIV tests, and consultations on HIV. Sometimes hepatitis B and C, syphilis tests, and pre-exposure prophylaxis (PrEP) were provided. Several countries (Armenia, Georgia, Moldova) also developed an extended package of HIV prevention services, which included consultations with endocrinologists on hormonal replacement therapy, mental health specialists, or lawyers on legal gender recognition. Many trans people prioritize the latter services over HIV, and providing them together was regarded as a means to engaging them in HIV programs: “These fields are very much intersectional, interconnected: the legal sphere, psychological sphere, and HIV. These services could be a motivation for trans people to get engaged in HIV prevention” (ARM). A holistic approach to healthcare is key to working with trans beneficiaries, and this distinguishes trans people from other populations:

If you wanna prevent HIV, it cannot be done the same way as you do it with cisgender people. . . Without a comprehensive view of healthcare you cannot just distribute condoms to trans women or non-binary people. There is a need for a comprehensive view on healthcare, which includes HIV prevention, mental health services, and gender-affirming care (GEO).

Echoing Maslow’s hierarchy of needs (Maslow, 1954), respondents believed that satisfying more basic needs was required to think about higher-level needs:

Until a person solves his problems, he does not need a test. . . And then he will think: “Oh yeah, let me think about HIV-related health, let me take a test, let me take a condom, let me take PrEP” (MDA).

Prevention services were typically provided by NGOs, which were considered to be a more convenient place for trans people to receive them than state-run clinics. On the other hand, HIV treatment was generally provided in state-run AIDS Centres. The funding generally came from the Global Fund, although a partial transition to state funding was in process in several countries. Wherever the funding came from, recognizing trans people as a key population was a prerequisite for coverage of an extended package of HIV prevention services, which is the topic of the next section.

### 2. Advocacy for the recognition of trans people as a key population

In addition to funding trans-specific services in an extended package, as described above, the need for recognition was explained by the aversion of many trans people, mainly trans women, to being considered part of other key groups, particularly MSM. An activist with experience working in HIV programs in Kyrgyzstan recalled:

There was no transgender group. There were certain codes; for example, 2 meant MSM. . . And when trans women came, we had to designate them with 2, and they expressed outrage. I remember they told me personally: “We are not men, why are you tarring us with the same brush?” (REG1).

These demands emerged around 2015. Before that, no such issues were raised in Kyrgyzstan. This might be explained by the lack of self-consciousness among trans people as a group:

Before that, there were only a few of them, and if they grouped together, they were very far away from activism, they were invisible for prevention programs, lived isolated, and were engaged in their own business, mainly sex work. But during these years, groups of activists from among the community started growing. . . It changed their mindset, that they have rights, they can demand something (REG1).

Yet, even when trans people made demands, they did not express them in a way that was understandable to policymakers:

People from the community could not say: “Separate us in the CCM as a separate group, so that they create for us a separate complex package of services.” They could not say this way. But when they said: “Why do you tar us with the same brush?” (REG1).

Thus, activists were required as “translators” of the community’s needs into the technical language of policymakers. These activists were generally willing to involve the community and receive feedback. An activist from Kyrgyzstan explained:

The community at that time had no understanding what is the CCM and why being represented is important. . . And when we explained it to the community, the community, of course, react positively, and they also understand that we have to be separated (KGZ).

A similar situation occurred in Kazakhstan: “Of course, it is very difficult for the community in terms of documentation, legislation. Thus, we prepared this all, informed them, and asked how relevant it was” (KAZ). Involvement of trans communities in decision-making was performed in semi-formal ways via elections. For example, in Kyrgyzstan, members of key population groups, including trans people, were allowed to elect their representatives (a member and an alternative member) to the CCM. In Kazakhstan, a Council of Trans People was elected by trans communities. The Council organized discussions with trans communities on important issues, including HIV. The activists tried their best to achieve the best inclusion possible by paying travel expenses for participants from distant regions to attend in-person voting or organizing online surveys/focus groups. In Armenia and Tajikistan, activists conducted needs assessments, which informed their advocacy.

Community-building processes and self-awareness as a separate group with specific needs have been unevenly developing in EECA. In countries where trans communities were not as cohesive, the initiative to recognize trans people as a key population came from activists without significant community involvement. For example, in Moldova, the process was initiated by a cisgender gay activist:

I suggested that here we should better include and involve a trans person. Of course, there were no such... there were trans people, but none of them were informed, prepared for such large-scale and official documents. But we managed, with the help of experts. And thanks to our participation, the Standards now define a separate group of trans people (MDA).

The success in Moldova was assured by the support of local branches of USAID and the World Health Organization. In other contexts, international organizations were the first to push the issue. In Russia, the only EECA country receiving money from the Global Fund via the so-called non-CCM consisting of civil society representatives without governmental involvement, the decision to recognize trans people as a key group in the grant application was forced by the Global Fund. A trans woman, who had been involved as a representative of another key group, was forced to make a coming-out to explain to others who were trans people and what needs they had:

The secretary of the CCM clearly articulated that in the next application, we must include trans people. Because otherwise they will simply reject the application. And the people sitting there were saying: “We have no trans people. Where do we get them? How do we approach them?”. . . Then, the facilitator asked me to make a forced coming-out. I said: “I am a trans girl, there are trans people among you” (RUS).

As a result, the Forum of Trans People, a non-official group responsible for the distribution of Global Fund’s money, was established. A similar situation occured in Azerbaijan, where “[for the Global Fund] to provide funding, the trans community must be included in the list of at-risk groups” (AZE).

When questioned about any opposition or negative attitudes toward the recognition as a key group on behalf of trans people, most respondents expressed great surprise and could not recall any such situation:

Key population recognition is about... You have more services for them. I do not know of any country in the world where there are key population-specific programs and mobilizing resources for trans people or any other group that causes any negative response from the community (GEO).

Another respondent said that there were only two types of attitudes in the community:

Either it is a group that needs programs and they say it is great. Or it is a group who are indifferent: if you do not need, you do not care. But to say “With HIV programs you are spoiling my life” — I have never seen that (REG1).

Later, he added:

We probably do not have studies on Uzbekistan, Turkmenistan. Maybe there were situations when they said that HIV programs were evil. There is this practice: an HIV-positive status is a cross on the person, when it discloses the second status. . . you are either an MSM, a sex worker, or a drug user (REG1).

Unfortunately, no respondent from Turkmenistan was present to confirm or refute this hypothesis. The respondent from Uzbekistan confirmed that such worries were justified but also believed that the benefits outweighed potential harm:

We consider the recognition of trans people and MSM as separate categories necessary for access to HIV services. . . We understand that stigmatization of these groups in civil society might grow and negative associations will be once again reinforced. However, all kinds of information related to HIV (statistics, budget shares, services provided, etc.) are rather restricted, it is not published anywhere (UZB).

One respondent even called negative attitudes toward visibility in the HIV sphere the lot of privileged individuals who did not understand the problem:

I have never heard people say, for example: “Oh, they are counting us again, as if we are spreading something, as if we are in some strange at-risk group.” I consider this a very privileged form of thinking, I almost nowhere observe it. I observe it in a small group, usually cis women feminists, who say this. But these are very-very small groups who are not involved in HIV (REG2).

He further elaborated that recognition by the state improved the mood of trans people and provided them with opportunities: “They perceive it in another context: not as attention but as an opportunity for advocacy, approaching the officials, an opportunity to talk to them, demand rights, an opportunity to change the legislation on legal gender recognition, medical transition, etc.” (REG2). While backlash could occur, he believed that the low number of trans people was protecting them: “It is true that the media can easily use it and they do use it, building upon HIVphobia of society. . . I think people believe that they are too few... trans people” (REG2).

### 3. Research

Quantitative research plays a pivotal role in HIV-related trans activism. Numbers are used to plan prevention and treatment programs: “Without strategic information, we cannot plan. . . healthcare programs. With the Finance Ministry, all the time they have arguments: ‘How many people do you want this service for? What is included in this service?’” (GEO). Numbers are no less important when writing grant applications to the Global Fund:

When we were writing the next application, there were questions, they required the data that in logic we had to take from the IBBS [integrated bio-behavioural survey] that we should have conducted. But the IBBS was not ready, trans people were not included, so we had to make things up (RUS).

Another sphere of application is advocacy. The data collected as part of a study are perceived as more credible than the mere words of activists:

To enter the circle of decision-makers. The only platform that we had at that time was the CCM. How to enter it? You always need data, so that you have something to show, you need data, you need numbers, you need research (KAZ).

Using the results of these studies, activists could achieve recognition of trans people as a key population in several countries and become members of the CCM. The usefulness of these studies depended in part on the reputation of researchers and their affiliation with international organizations or state-run institutions:

The image that it is an international organization, it is better perceived by the officials... And if a sociologist with a rather long CV... These things allow to reach decision-makers much more effectively. . . HIV studies have very specific requirements, including that they should be conducted with the participation of the country itself, an official healthcare institution. And they very much take them into account, if they are at least formally involved (REG2).

Even the mere fact that a study was being conducted could positively affect the community: “These HIV-related activities, they even positively affect the mood of trans people. Because trans people feel that they receive interest — from NGOs, from donors, from international organizations, and from the state” (REG2).

When asked how reliable the numbers obtained in these studies were, most respondents admitted that they were not: “It is basically impossible to determine the number of trans people. Criminalization, high levels of transphobia, the lack of basic knowledge about trans people, and stereotypical attitudes within the LGBTIQ+ community itself make it impossible” (UZB). In conservative contexts, trans people frequently travel (including migrating abroad) to avoid discrimination, which makes it hard to count them: “We cannot tell how many of them there are. They frequently change their place of residence. Sometimes they appear, sometimes we meet them in 3–4 years” (TJK). Quantitative assessments can further be hampered by major cataclysms: “In Ukraine, the population estimation coincided with the COVID pandemic, access to anyone was severely limited. . . Now the war” (UKR). Another respondent explained further reasons why trans people in EECA were hard to reach and therefore accurately counted:

People are afraid to participate in studies, they do not trust, or they are busy surviving and working. They have very low motivation, they very poorly understand how coming to some office to give blood for an HIV test, how it is connected to policy change, to improvement of NGOs' work (REG2).

Often, the quality of studies also depended on the availability of funding:

Either there is no money to hire a good research team, make a pleasant office, tea-coffee for those coming to participate. Or another part: the country has such a situation, trans people have a low economic level, and for years they have been accustomed to receiving money for participation. As a result, when a study has no money, no motivation package, they simply do not participate (REG2).

While the participation of the state was welcomed, it could sometimes scare off trans participants:

If the state participates, it can participate in a not very friendly way. Medical specialists can poorly understand the terms, how to talk to people. They can push a person away from participating without a special desire. And since we are used to peer-to-peer communication, we trust each other, we quickly transmit information within the community, just like other marginalized communities. One person hears an incorrect question (e.g., “Are you a boy or a girl?”), he will go and tell everyone, and they won't participate (REG2).

These problems often led to a great underestimation of the number of trans people. For example, a recent study in Kyrgyzstan found 56 trans individuals (Solpueva et al., 2022), whereas in Armenia, the number was 150 (Papoyan et al., 2018). When the community found the number too low or too high, they could enter negotiations and ask for a new study:

They just say: “No, it cannot be like that. Let's roughly accept it, but we will conduct a study again. And we all agree, all the community agrees that we do not concur with this number, it is a wrong number, because, because...” It works. Because it is logical that the community better knows, feels whether this number is close to being true (REG2).

It really worked. In Armenia, activists insisted on a new study that resulted in a new estimate of 1015 trans people instead of 150 (Davtyan et al., 2021). The reason for such a discrepancy was explained by social and political change:

After the revolution, the staff was changed and more competent staff members were hired by NCID [National Center for Infectious Diseases], and also I would mention the development of trans activism in Armenia within this time frame, because new trans leaders and activists emerged (ARM).

While recognizing the deficiencies in size estimations, most respondents did not find it a serious problem since their purpose was not to determine some “real” number of trans people but the number of individuals who needed help: “If you ask me: ‘Do you know how many trans people live in Georgia?’ I cannot answer that. But with this study, I can tell you how many people are trying to access any services” (GEO). There was only one respondent who tended to trust numbers from different studies. According to him, mere inconsistencies in numbers between countries were not an argument to question their reliability:

If, for instance, in Ukraine, there are 3% trans people, it does not necessarily mean that in Georgia it should also be 3%. I think it can greatly vary from country to country depending on the context. For example, a lot depends on how open the country is, how friendly its laws are (REG1).

Research is not the only source of quantitative information about trans people. Numbers can be obtained from the regular monitoring of HIV programs: How many participated in the organization’s activities? How many received condoms? How many took HIV tests? However, these data could also be far from reality:

There can be doubts. . . how diligently these organizations do their job. . . These prevention programs, they are too often aimed at indicators. Suppose they must provide means [of protection] (condoms, lubricants) to 300 individuals each month. Are there 300 individuals each month or not? No one cares (REG1).

Low salary and motivation of outreach workers coupled with inefficient monitoring systems were named among the reasons for manipulating numbers. Often, the number of beneficiaries covered depended on the personal background of outreach workers. For example, having experience in sex work and migration helped one respondent reach more beneficiaries than another trans woman without this experience:

<Name of the outreach worker> worked in <name of NGOs>, she was a trans woman who worked specifically with trans people. They could not reach the indicators. . . Then I started working, and the focus was specifically on trans sex workers, most of them were migrants. . . I do not remember how we reached those indicators (RUS).

Many trans people were afraid to contact NGOs, which could also lead to underestimation:

Currently, individuals who contacted HIV service organizations claim that they have never been in such organizations and substantiate this with the fact that they had heard about negative experiences of friends/acquaintances who had problems after disclosing their identity or orientation in these organizations (UZB).

Another source of quantitative information is state-run AIDS Centres. However, only HIV-positive individuals tended to visit them to receive ARVT. Even they tended to avoid state medicine when possible: “There were big complications with specialists at AIDS Centres. When a person comes and this person feels absolutely uncomfortable because they require [identification] documents... They record into another key group, for example, MSM” (KAZ).

Qualitative research is less widespread in the HIV sphere but can also be used, especially in countries with fewer trans people. For example, in Armenia, activists conducted a focus group discussion to understand the barriers and needs of trans people in order to develop a trans-specific HIV package. In Kazakhstan, activists conducted a mixed methods study on HIV risk-factors (for the results see Shenker et al., 2022). In Uzbekistan, activists inquired about the effect of criminalization of same-sex relationships among men on their motivation to undergo HIV testing.

### 4. Sensitizing doctors

Fearing mistreatment, trans people rarely visit doctors in relation to HIV, preferring to receive prevention services from NGOs. However, for HIV-positive individuals, there is no choice but turn to the healthcare system, particularly the state-run AIDS Centres. To sensitize doctors, NGOs conducted trainings and accompanied their beneficiaries:

We accompanied transgender people with HIV-status to clinics multiple times. . . In the beginning, it was a bit difficult for the doctors to get used to identifying how a person wants to be referred to. But they got accustomed (MDA).

Since it was not possible to educate all doctors in the country, NGOs had a limited number of friendly doctors who specialized in trans issues:

In the AIDS Center, we have certain doctors. And when someone comes by referral from our organization or they decide that it is a transgender person, they are referred to certain doctors. We have three to four doctors who work exclusively with our group” (AZE).

The lists of friendly doctors (not just HIV specialists but also endocrinologists, urologists, gynecologists, cardiologists) were shared privately for safety reasons:

These specialists, who understand the general picture of discrimination against LGBT people and who are ready to work with them within the country, are not ready to openly declare their commitment. Thus, information on these specialists remains confidential and accessible only in close circles (UZB).

Azerbaijan’s shows the consequences when information about friendly doctors becomes known to people outside the community:

We educated two doctors, sent them abroad; these doctors were endocrinologists. But then there were big problems with the parents of trans women. They came to their workplace, threatened them: “You are transforming our sons into women, giving them hormones.” And people just refused to work (AZE).

### 5. Uncertain and intersecting identities

The respondents confirmed that there were individuals who were unsure about their gender identity or changed their gender expression. It was more common in authoritarian countries where these individuals had poor access to information and public expression in a gender different from the sex assigned at birth was unsafe. In the case of Tajikistan, individuals changed their gender expression when going abroad and returning back:

Transition, body correction, top, bottom surgery (most trans women mostly do top) is unsafe. Those trans women who went to Russia, there they do top correction, surgeries, there they are doing sex-work. When they have to return to Tajikistan, they have to do [mast]ectomy, remove everything (TJK).

When approached with the question to which categories should be placed individuals who were unsure about their gender identity or belonged to more than one key group, the respondents gave very simple and straightforward answers. In cases when beneficiaries were unsure about their identity, they could be referred to a psychologist to “uncover” their true identity as if it was something given:

They first cross-dressed as a woman, put on make-up, thought: “Maybe it is travesti.” For this reason, we referred [to a psychologist], and they indeed started identifying themselves differently. . . [Interviewer: How did they receive services, as trans people or MSM?] First, they came as MSM but then switched to trans (MDA).

Trans people belonging to other key groups could choose where to receive services:

The questions of identity, they are the most difficult because putting into boxes in general is a rather difficult practice. . . But if we talk specifically about prevention programs, how to identify them when, for example, referring them to one or another program, here, I think, the issue is actually not difficult. It is always done on the basis of how a person self-identifies. When a person comes to an organization, he or she is told: “There is a certain group, for example, a group for MSM, for transgender people, for sex-workers or drug users. With which group do you identify and where do you feel more comfortable?” (REG1).

Often, NGOs specialized in providing care for certain key groups, so beneficiaries belonging to more than one group could receive services in different places: for example, condoms and HIV tests in an LGBT organization, while clean needles in an NGO for drug users. Yet, in practice, it did not work as perfect:

It is a very big problem that transgender sex-workers cannot receive everything in one place, satisfy their needs. To receive services for sex-workers they have to turn to sex-worker organizations and encounter possible transphobia there, and to receive services as trans people, they turn to organizations for trans people where they can encounter stigma as sex-workers (RUS).

Trans people were also forced to choose between their intersecting identities when participating in the Forum of key groups in Kyrgyzstan: “A person had to decide for himself. He could only be part of one forum, one key group, he cannot... They were conducted simultaneously. He could not sit here, vote here, then go vote elsewhere” (KGZ).

### 6. Using HIV for advocacy on other issues

HIV was used to advocate for other issues (gender-affirming care, legal gender recognition) as it helped build connections and receive money: “Entering the CCM and the dialog on HIV in general, in my opinion, is related to gender-affirming services. It is immediately linked to two issues: access to decision-makers, and second, of course, access to funding” (UKR). This link was especially vital in political contexts, where talking about trans rights directly was not possible:

The hottest issue for us is our lives, our safety, our health... And since it depends on laws, officials... But since they are not ready to talk about rights, but are ready to talk about HIV, then this way. Here is the loophole. . . The HIV door is open, human rights — no. Thus, you need to break into, so that you can do something (REG2).

This was possible because of the causal relationship between medical and legal transition, on the on hand, and HIV outcomes, on the other. One respondent explained that the willingness to listen to activists on HIV was caused by the officials’ care for the general population, not the key groups:

It is, of course, bad that we are bowing down to the system, as it is, because HIV issues... they are perceived by the state and society in a way that if we do not conduct prevention among key groups, HIV will spread among the general population (REG1).

### 7. Barriers for HIV-related trans activism in the region

The respondents reported three types of challenges: disinterest of trans communities in HIV issues, repression by the state and society at large, and rejection within the civil society working on HIV issues.

Most trans people took no active role in HIV prevention and treatment: “Not all trans people believe that HIV has anything to do with them. Take, for example, the transmasculine community. Not everyone is ready to get involved. As if they are tired of this topic or the approaches are out-of-date” (KGZ). Awareness was higher among trans women, especially those involved in sex work:

If you take my communication with trans migrant sex workers, they know [about HIV] because it is directly interconnected, so they get tested consistently once or twice a year. It is an achievement: they call us, come to receive condoms, lubricants (RUS).

However, involving trans sex workers in activism was difficult because NGOs could not compensate them with a salary equal to their income as sex workers and their working hours did not overlap: “They can earn in one day 1–2 monthly salaries that we can offer them. Thus, we cannot motivate them with money. . . And when they do sex-business, they wake up around 5–6 in the evening” (AZE).

This leads us to another type of challenges — those imposed by the state, which result in underfunding as one of the consequences. In countries such as Azerbaijan, Belarus, and Uzbekistan, NGOs must report to the state authorities any funding received from foreign donors. In Tajikistan, trans activists were afraid to receive funding from local donors, including the local branch of the Global Fund, out of fear that their activities would be reported to the Ministry of Justice, leading to prosecution. In Kyrgyzstan, the CMM was temporarily disbanded after one of its conservative members drew attention to the fact that Global Fund’s money was used to promote MSM and trans rights:

She initiated a conversation at the meeting of Zhogorku Kengesh [Supreme Council] that. . . most money is received by the UNDP and NGOs. . . We cannot control them. . . Why in this grant application are there MSM, sex workers, and trans people? Our country supports traditional values (KGZ).

In Russia, the law on “foreign agents” and Western sanctions made it difficult to receive international funding. Recently, laws banning the “propaganda of the change of sex,” gender-affirming care, and legal gender recognition were introduced, leading to massive emigration abroad and the isolation of those remaining:

Many trans people panic, they want to run away, go abroad. . . The club where we conducted outreach, is about to close or they refuse to collaborate with organizations allegedly related to LGBT. The community itself goes to the closet, they stop making contact with organizations, even in the HIV prevention sphere. In general, the mood is depressive (RUS).

In Armenia, activists became targets of physical attacks:

We as an organization are targeted by extremist groups, the members of our organization are targeted for providing services. I can give a fresh example of how a trans outreach worker who was conducting HIV prevention activities in these sites where trans people gather was brutally beaten (ARM).

As for the third type of challenges, trans people faced stigmatization in the HIV sphere, which is still dominated by men, many of them former prisoners who were convicted for using drugs:

To get into this [HIV] world. . . You should have a certain image. I know for sure that, especially in Central Asia, these prison attitudes influence how LGBT organizations are perceived. Since the 1990s, when HIV organizations started coming into being, organizations of drug users have continued to be coordinated by men. . . And there is an atmosphere, in which they do not want to shake hands [with us] (REG2).

This lack of cooperation meant that trans/LGBT organizations often found it difficult to receive funding from the Global Fund. In Tajikistan, larger NGOs could use their contacts with the authoritarian state to eliminate competitors: “An organization that every year receives [money from the Global Fund] can obstruct our way indirectly using law-enforcement authorities, the KGB [Committee for State Security]. We had such a bitter experience” (TJK). In larger HIV NGOs, trans people cannot make a career progression: “HIV service organizations try to employ trans people. However, they are always just outreach workers, they never hold managerial positions” (RUS).

Fearing stigmatization if trans people were included, members of the broader civil society were willing to sacrifice trans inclusion for the well-being of other key populations:

They introduced key groups that needed shelters, rehabilitation centres, specifically for women. And [name of the activist] wanted to include trans women. But it did not pass. Right during that working group meeting, our partners, allies said: “We understand everything, but with you, our decree will not be adopted” (KAZ).

In Moldova, the CCM members were also guided by more general principles that inhibited the inclusion of a quota for trans people:

We explained but in the CMM, there are already too many people. They want to reduce it because there are too many members. And if we send a trans person, the representation of the civil society would be higher than that of the state authorities. There won't be a balance (MDA).

## Discussion

The study identified four interconnected spheres of HIV-related trans activism: provision of services, advocacy, research, and working with doctors. To improve the quality of services, activists sensitized doctors and engaged in advocacy to make the state recognize trans people as a separate key group. Such recognition would make HIV services more affordable (because of specifically allocated funding) and acceptable (because trans women would be recognized as women, not MSM). To underpin their advocacy, NGOs conducted research that made their claims better founded. In addition, trans population estimates were used to plan programs and write grant applications.

When working on HIV issues, activists faced the following challenges: lack of interest in HIV issues among trans people, repression by the state and physical attacks, and lack of support by civil society. While trans communities in general did not prioritize HIV, it was more important for trans women, especially sex workers. Yet, engaging them in activism was not easy. The composition of the sample itself substantiates this conclusion: of 12 participants, only one was a trans woman (if the respondent from Belarus answers, there will be two). Activists faced hostile attitudes on behalf of state authorities, society at large, and civil society in particular. However, no generalization about the region should be made on the basis of these findings, as the countries’ political situations varied.

When answering the first major research question of this paper “What are the attitudes of trans communities and activists toward the recognition of trans people as a key group vulnerable to HIV?”, the results showed that their attitudes were mostly positive. Being a separate group gave them a feeling of recognition of their identities and specific needs. This finding agrees with studies in other regions, which emphasize the importance of separating trans people (and especially trans women) from other groups such as MSM (Sevelius et al., 2016). A novel finding of this study was the use of recognition as a separate group as a vehicle for receiving trans-specific services such as hormonal replacement therapy and consultations with endocrinologists, psychologists, and psychiatrists. While the calls to combine HIV services with gender-affirming and mental healthcare services have been made during the last decade (e.g., Sevelius et al., 2014), this article shows their practical implementation in EECA. Capitalizing on the link between HIV and trans-specific issues (access to hormonal therapy, surgeries, mental health services, legal gender recognition), some activists strategically used the former to promote the latter. Such an approach was especially relevant in more conservative countries, where talking directly about trans issues was not possible and HIV issues were used as a gateway to reach decision-makers. Only three respondents recognized the potential harms of being labelled as an “at-risk” group in the form of stigmatization (for more on this view see, e.g., Shoveller and Johnson, 2006), even they confirmed that such a view was not widespread in the communities.

When answering the second major question “What do activists think about the reliability and utility of quantitative studies in the HIV sphere?”, the results showed that most activists were aware of their shortcomings. Among the reasons prevailed factors making trans people a hard-to-reach population: the lack of trust toward NGOs and (especially cisgender) researchers, the lack of motivation to participate (if the long-term benefits of the study were not understood or no financial compensation was provided), and frequent change of the place of residence. Similar barriers to participation have been reported in previous studies (Owen-Smith et al., 2016). On the other hand, the respondents were less likely to recognize the inherent uncountability of the trans population. When asked directly, they gave very simple and practical solutions to what to me as a researcher seemed to be very complex questions of identities and boundaries. For example, individuals unsure about their identity could be referred to a psychologist to uncover who they “really” were. If a person first thought of themselves as a cisgender gay man and then transitioned to become a trans woman, that person was counted and received services first as an MSM and later as a trans woman. Likewise, individuals with intersecting identities could choose whether they would be more comfortable receiving services as representatives of one group or another. How satisfactory these simple solutions were for the beneficiaries of NGOs is another question that requires a follow-up study. However, based on the data available, activists did not share critical attitudes toward population size estimates in general found in the literature (Biruk, 2022; Davis, 2020; Kavanagh et al., 2018), even when recognizing their shortcomings.

The advantage of this study is its focus on the intersection of HIV and trans issues in the underexplored region of EECA through the eyes of activists. It gives insights into how activists on the ground perceived and used quantitative research and categories such as MSM and trans — none of those having originated in the region but brought to them from abroad. The study’s main drawback originates from the attempt to cover all the complexities of HIV-related trans activism in 10 countries in one paper. Interviewing just one person per country is certainly not sufficient to provide a detailed picture of all the undercurrents and controversies that exist in any social movement. Hopefully, this article will serve as a starting point for future in-depth explorations of the aforementioned questions at the national and subnational levels.

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1. In this text, EECA includes the following 12 post-Soviet countries: Armenia, Azerbaijan, Belarus, Georgia, Kazakhstan, Kyrgyzstan, Moldova, Russia, Tajikistan, Turkmenistan, Ukraine, and Uzbekistan. [↑](#footnote-ref-2)