

## **PROMISE: Promoting Youth Involvement and Social Engagement: Opportunities and challenges for conflicted young people across Europe.**

**WP6: From Conflict to Innovation: Ethnographic Case Studies**

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### **People living with HIV and HIV activists (St. Petersburg & Kazan)**

#### **Russia**

**Nadya Nartova, Iskender Yasaveyev, Anastasia Shilova**

**Center for Youth Studies, NRU 'Higher School of Economics'**

**St. Petersburg**

**Executive summary:** Today, around 36 million people live with HIV. Despite the existence of a global strategy to end the AIDS epidemic by 2030, the situation in Russia is critical. Officially, by November 1, 2017, 1,193,890 cases of HIV infection had been registered among Russian citizens. Given the moralising discourse created by the state with regard to HIV-positive people and the spread of the virus, HIV activism plays an important role in developing and preventing the epidemic.

Our goal was to study the structure, actors and their strategies of HIV-activism. Two locations were chosen: St. Petersburg; and the Republic of Tatarstan. St. Petersburg is one of the Russian regions most affected by HIV, while the Republic of Tatarstan is recognised as one of the safest regions in the country with regard to the spread of HIV. However, both in St. Petersburg and Tatarstan, there is rapidly developing HIV-activism.

The collected data include 29 semi-structured biographical interviews and 28 days of observation. The study shows that, despite the stigmatisation and high level of control over the actions of civil society, a heterogeneous but solidary HIV activist space is developing. The structure of the HIV activism field is set by officially registered NGOs and informal network associations, depending on the direction of its activity. Being key figures in the community, activists create a comfortable and safe environment for various groups of people with HIV. Activists organise support groups, individual counselling and support, outreach work, provide medicines in emergency situations, etc. Thus, the emerging HIV community is becoming, in a sense, a communication space, which is important for both activists and community members in maintaining their identity, recognition and belonging.

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## 1. Introduction

The first clinical data on the disease later called HIV infection were recorded in 1981. The human immunodeficiency virus (HIV), which causes this disease, was discovered in 1983. Since then, about 78 million people have been infected with HIV and approximately 35 million have died (UN, 2018). UNAIDS estimates that in 2016, around 36.7 million people worldwide live with HIV, 20.9 million of whom are receiving antiretroviral treatment (UNAIDS, 2018). Today, both the scientific community and international organisations focus on the regions of Asia and Africa with more than 30 million HIV-positive people (19.4 million in East and South Africa) (UNAIDS, 2017: 14). At the same time, Russia is experiencing a critical situation comparable to that in South-East Africa, which, nevertheless, has almost completely fallen out of the research focus both at the national and international levels. According to UNAIDS, Eastern Europe and Central Asia are the only regions where the HIV epidemic continues to grow rapidly. Moreover, more than 80% of new HIV infections in these regions occur in Russia (UNAIDS, 2016: 170–173).

According to regional AIDS Centres, by December 31, 2017, 1,220,659 cases of HIV infection had been registered among Russian citizens, including 550,000 in 2012–2017. In 2017, 104,402 new cases of HIV infection were reported (excluding anonymous cases and cases of foreign citizens) which is 2.2% more than in 2016. About 277,000 people with HIV died. The number of people living with HIV who know about their diagnosis had amounted to more than 944,000 by January 2018. In 2017, for the first time, the share of heterosexual contacts as a risk factor for the infection (53.5%) exceeded the share of drug use by non-sterile instruments (43.6%) among ‘newly identified in 2017 HIV-positive people with established risk factors for the infection’ (Rospotrebnadzor, 2017: 3). According to V. Pokrovsky, Head of the Russian Federal AIDS Centre, about 500–600,000 people in Russia live with HIV, without knowing about their status (Mishina, 2016). The number of HIV-positive people, thus, may total more than 1.5 million.

However, state officials do not consider the current situation critical or call it an ‘epidemic’. The state creates a moralising discourse with regard to HIV-positive people and the spread of the virus, which sets a nationwide stigmatising and marginalising rhetorical framework. The reinforcing rhetoric of ‘traditional values’ as the main way of regulating infectious diseases among other things is manifested both in separate statements by politicians and in state documents. In 2016, the government approved the ‘State Strategy for Counteracting the Spread of HIV Infection for the Period until 2020 and for the Longer Term’. Despite the fact that one of the objectives of the Strategy is to increase citizens’ awareness of HIV and create a social environment without discrimination against people infected with HIV, it uses traditionalist rhetoric (*‘to strengthen traditional family and moral values’*), which contradicts the anti-discrimination agenda, and does not contain any provisions on sexual education, harm reduction programmes, or replacement therapy (State Strategy, 2016). This view of the HIV/AIDS situation, from the standpoint of ‘traditional values’, narrows the possibilities of spreading information about the epidemic and supports treating HIV-positive people as deviants. This is illustrated by an example of the kind of slogans used in promoting anti-HIV messages captured in Plate 1 (below). The poster reads ‘The greatest weapon against HIV is love and loyalty’.



Plate 1. One of the slogans of the ‘Stop HIV/AIDS’ campaigns held by the Foundation for Social and Cultural Initiatives under the supervision of S. Medvedeva in 2017.

Another important structural condition that determines the context of life of HIV-positive people is legislation. The law on the prevention of the spread of HIV infection was adopted in 1995, and many activists believe it to be outdated and to infringe people's rights, despite the amendments. This is primarily due to the restriction of professional activities, restriction of entry into the country for HIV-positive foreign citizens and their deportation if they do not have any close relatives.

Moreover, in recent years, legislative initiatives significantly affect the activity of civil society. For example, the legislation on public events has been tightened up; coordination of public events has become more complicated and punishment for unauthorised actions more severe (from fines to imprisonment for up to 5 years). The legislation regulating the activities of NGOs has been changed –there is now a law that requires organisations which receive foreign funding to register as ‘foreign agents’, which entails stricter government and financial inspections, restriction of activities and stigmatisation in the public eye. This law resulted in the persecution and closure of a number of civil and research NGOs in Russia, reduction of their funding sources, creating an atmosphere of danger, where an organisation is likely to be closed if its activities, including its financial sources, cease to satisfy the government. The amendments, known as the ‘Law on Unwanted Foreign and International Organisations’, resulted in a situation where many humanitarian international organisations and foundations, including those supporting the fight against HIV/AIDS, had to limit their activities or close their offices in Russia.

Cultural and legislative stigmatisation of a number of social groups in Russian society significantly limits the possibility of working with them. For instance, drug use and sex work are criminalised and marginalised, which impedes access to these groups in order to prevent the spread of HIV. In addition, the ban imposed in 2013 on ‘the promotion of non-traditional sexual relations among minors’ actually criminalises discussion of LGBTQ+ issues in public and limits the possibility of informing the public about the ways of HIV transmission, since the part connected with sexual transmission cannot be properly discussed without a threat of being prosecuted under this law.

Thus, HIV-positive youth and young adults live in the conditions of an epidemic, the rhetoric of ‘traditional values’ and the discourse of amorality towards people with HIV, weak state policy regarding HIV/AIDS and repressive legislative regulation of civil society. At the same time, HIV activism, which appeared in the mid-2000s and is aimed at protecting the rights of HIV-positive people, continues to develop and prevent HIV/AIDS, even under these difficult circumstances. The overall goal of the project is the study of the role of young people, especially marginalised and stigmatised ones and those who are in a conflict, as an initiator of social changes in modern society. Taking into account this goal, we have chosen the HIV community, which is one of the problematic and stigmatised groups in modern Russia. Within this case, it was important for us to answer the questions: How is the space of HIV activism in modern Russia organised? Who is involved in it and why? What are their challenges and how do they react to them?

## 2. Methods

Two locations have been chosen for the study: St. Petersburg and the Republic of Tatarstan (its capital, the city of Kazan). St. Petersburg is the second largest city in Russia in terms of size, development and infrastructure, and one of the Russian regions most affected by HIV. Incidence of HIV infection (the registered number of HIV-positive people per 100,000 residents) in the city was 981.9 as of December 31, 2017, while in general in Russia it was 643 (Rospotrebnadzor, 2017: 2).

The Republic of Tatarstan, on the other hand, is recognised as one of the safest regions in the country with regard to the spread of HIV. Although much higher rates of infection have been registered in the three South-East regions of Tatarstan (in Bugulma (847.5), Almetyevsk (565.2) and Leniogorsk (501.7)), in the Republic of Tatarstan as a whole, the current HIV incidence is much lower than the average for Russia, 336.8 (in Kazan – 393.6) (Weekly epidemiological situation, 2018). Moreover, the Republican AIDS Centre in Kazan is considered the best in Russia.

However, both in St. Petersburg and Tatarstan, unlike many other Russian regions, there is rapidly developing HIV-activism aimed at resisting the epidemic and helping HIV-positive people.

The main research method we used is a case study, which comprises participant observation and audio-recorded deep biographical interviews. The primary access to the field in St. Petersburg was conducted through researchers' social networks and in Tatarstan through a key informant: an HIV activist Svetlana Izambaeva, living with disclosed HIV-status, who is the organiser and coordinator of support groups for HIV-positive teenagers and women. Subsequently, social networks of informants were also involved.

In order to establish trust and be included in the community in both cities, researchers volunteered in the organisations. However, this role was overt not covert. The Svetlana Izambaeva

Foundation provided assistance in photographing and video recording of trainings, writing letters, news about current events for the website, discussing the 'theatre project' (a performance/writing plays) involving HIV-positive children and discussing current situations. In St. Petersburg, one of the organisations was assisted in conducting a small sociological survey initiated by this organisation for their internal purposes.

In total, 29 semi-structured biographical interviews with activists, NGO workers, and their leaders were conducted: 10 of them in Kazan and 19 in St. Petersburg. 14 women (5 in Kazan, 9 in St. Petersburg) and 15 men (5 in Kazan, 10 in St. Petersburg) were interviewed. The age of the respondents ranged from 18 to 51. This included: ten people under 30; 15 between the age of 30–40; and four over 40. The preliminary research analysis of open sources (texts and photographs on NGOs websites, media materials, etc.) made it possible to assume that mainly young people were involved in HIV activism. However, the fieldwork showed that at the moment, the core of HIV activism is formed by young adults aged from 20 to their mid-30s who have been involved in HIV activism for the last 10–12 years. Thus, the average age of informants of the case is slightly higher than the one targeted in the project. Nevertheless, we believe that this can still be considered youth activism, as: a) current active participants became involved in activism when they were young; b) the study shows that there is a significant proportion of young people involved in HIV activism; c) a significant part of the activity is oriented towards young people, including those age groups that, according to the ethical clearance of the Russian team, could not participate in the study as informants (since they were under 18).

The length of the interviews varied from 50 to 145 minutes. The total length of interview recordings amounts to approximately 38 hours. It should be noted that all informants have different class, educational and social backgrounds. The group includes people with higher education, students, and people with only secondary school education. There were members of high and low-income families, as well as individuals with an addiction or criminal past. However, they are all united by the fact that at the moment, each of them is involved in the work of HIV NGOs and HIV activism.

Prior to the interview, each respondent had been informed about the purpose of the project, as well as about the fact that the interview would be recorded and subsequently transcribed word-for-word, anonymised and used for research purposes. No one refused to participate after that. All the respondents reacted well to the recording, and some of them even said that they did not mind the researchers using their real names. It is worth noting, however, that not all respondents were ready to draw a map of the field or mention specific names, when speaking about interaction among organisations. The ones who agreed often stressed that it was only their personal view of the situation and that they did not know the state of affairs in reality. Moreover, in the course of several interviews, informants asked to stop the recording for a while when talking about unofficial functions of their organisation's activities, its funding, etc.

In addition to the interviews, 28 days of observation were conducted (20 in Kazan, 8 in St. Petersburg). The total number of observation hours in Kazan amounted to about 46, while in St. Petersburg, the number was about 11. In Kazan, the events and practices observed included meetings with key informants (21.02.2017, 17.04.2017), training sessions with HIV-positive children who do not know about their diagnosis (25.02.2017, 22.03.2017), support group meetings of HIV-positive teenagers (26.02.2017, 5.03.2017, 12.03.2017), support group meetings of HIV-positive women (5.03.2017, 19.03.2017), meetings and trainings of school children, students of secondary and higher educational institutions held by HIV- activists (10.03.2017, 06.04.2017,

21.04.2017), a webinar of the international community Teenergizer (offline monitoring of participants on 18.03.2017), a training with parents, grandmothers and other family members of HIV-positive children (22.03.2017), a meeting of HIV activists and HIV-positive teenagers with the participants of the project *'Takie Dela'* (25.03.2017), meetings of HIV activists with the head and director of the theatre laboratory *'Ugol'* and discussion of theatre projects for HIV-positive teenagers (05.04.2017, 10.04.2017), preparation for a round table discussion with HIV-positive teenagers in Moscow (18.05.2017), a campaign of HIV activists for testing, distribution of leaflets and condoms in the pedestrian Bauman street (19.05.2017), an open discussion 'Attitude of the Public to the Issue of HIV' within the Kazan marathon (19.05.2017), the Kazan marathon with HIV activists as participants, who ran as a separate group in white T-shirts with a red ribbon (21.05.2017), and an event 'Dance4life' organised by HIV activists in a Kazan secondary school (26.05.2017). In St. Petersburg, the events included a dance flash mob, timed to the International Women's Day (5.03.2017), International AIDS Candlelight Memorial Day (25.05.2017), lectures on HIV infection held during various events (06.03.2017 and 27.05.2017), testing for HIV carried out by different organisations (20.02.2017 and 27.05.2017), as well as making a video for International Condom Day (11.02.2017).

The specificity of the field in St. Petersburg (the closed nature of the organisation, sensitivity to anonymity, orientation of some organisations to the men who have sex with men (MSM) community) did not allow researchers to conduct a traditional participant observation and, therefore, the study here was limited to participation in public events and several working events. For the same reasons, there was no photographing in St. Petersburg. In Kazan, photos taken with the permission of the participants during the observed events were included in the observation diaries. A total of 360 photographs and 3 videos were made. HIV-positive people apart from Svetlana Izambaeva, who is open about her HIV status, were photographed from the back to make sure they could not be identified.

In order to analyse the empirical data, narrative and thematic approaches were used in parallel. The narrative approach allowed attention to be focused on the narrative construction of identity. During the thematic analysis (Riessman, 2005: 2), we reconstructed common themes and events, as well as the dominant types of their interpretations, which allowed informants to describe their own experience and that of the community. Therefore, we could take into account both the factual biographical components and the values attached to experience and practices. The analysis of the empirical data has shown a similarity of the contexts, practices, interpretations shared and produced by activists in St. Petersburg and Tatarstan. The locations differ mostly in terms of the length of HIV activism, the size of the activist field and the effects caused by the size of the location (e.g. greater anonymity in the larger city), whereas the structure of the experience of activists differs to a lesser extent. In this report, we have focused on similarities, specifying differences when necessary.

### 3. Key Findings

#### 3.1 Stigmatisation of HIV-positive people

The basis and context for HIV activism is stigmatisation and discrimination of HIV-positive people. Throughout the study, during most days of observation and a large part of the interviews, members of support groups and informants living in Tatarstan and St. Petersburg told us about many cases of discrimination of their rights, negative attitude, aggression, violence, fear, and breaking of relationships, and moreover, a significant proportion of these cases were recent. The

contexts of stigmatisation and discrimination are very diverse: family, parties with friends, schools, sports clubs, health resorts, clinics, and hospitals.

The most frequent agents of stigmatisation are close relatives and friends. Quite often, becoming HIV-positive is one of the turning points in life, which is perceived as a litmus test showing who is who and separating 'real' friends from casual acquaintances. However, in some cases, even the closest people, including family, can turn their backs on a person because of the moral stigma with which HIV is often associated:

If, for instance, in Yakutia someone says that he is HIV-positive, this is the end. No one will talk to him anymore, he will lose all friends, even his family can abandon him... (Ivan, male, 29 y.o., St. Petersburg).

In a number of cases, HIV-positive people were not supported by close family members because of the fear of being stigmatised if the information spreads.

While telling her story, A. cried and said that she had not visited the [support] group for a long time; she came because she could not take it any longer, 'this is unbearable', she did not sleep at night, there was no work or family for her. When A. comes home [she lives 170 km from Kazan], her mother is displeased and asks her why she has come: 'Do you have much money to spend on trips?' A. says that it is better to live in Kazan, she is afraid that people [in this town or village] will find out about her diagnosis (Field diary, 5 March 2017, Kazan).

Although HIV infection is not an obstacle to undertaking the vast majority of professional duties, including in the medical professions, and HIV-positive people have equal labour rights, they are often subjected to various forms of labour discrimination. This can manifest itself as the requirement to take an HIV test and report the result (which is officially prohibited by the law), as well as dismissal or creation of conditions for dismissal if the diagnosis becomes known. At least once during the observation period, there was a dismissal in Kazan because of HIV status. The management of a private dental clinic forced a nurse to resign after finding out that she had HIV (Field diary, 6 April 2017, Kazan).

However, some of the key agents of stigmatisation are medical professionals. Activists emphasise the low level of competence and knowledge about HIV among medical professionals who are not specialists in the field, at all levels, from doctors to junior medical staff. It is in (non-specialised) medical institutions that HIV-positive people experience degrading attitudes and statements, are denied services and their confidential information gets disclosed:

In medical institutions, there is still this... I mean, they refuse to treat us still, although they already know that it is, roughly speaking, punishable, that this is illegal, nevertheless, they deny service. They do not want to bother. (Ksenia, female, 33 y.o., St. Petersburg)

Medical workers violate not only the law on provision of medical help but also the law on doctor-patient confidentiality. In a relatively short period, several months of observation and interviewing, informants spoke repeatedly about the disclosure of medical information, i.e. the diagnosis of 'HIV infection' by doctors and medical staff:

A year ago, a member of the mutual support group for teenagers L. went to a private dental clinic to get braces. Before the consultation, she filled out a questionnaire which contained the question whether the patient was HIV-positive. L. gave the affirmative answer, believing that she should report this. Recently, she has found out that the clinic administrator told her son, who knows L, about her HIV status. He, in turn, told this to other teenagers in the neighbourhood. L. has recently discovered that many teenagers with whom she spends time know about her HIV status, although she has not revealed this information ... L. said that, as a result, her boyfriend broke up with her. 'My grandma worried a lot, yesterday she was ready to file a law suit.' L. was smiling when she said that everyone had found out about her HIV status, but then she added, 'Now I am going to cry again'. (Field diary, 18 May 2017, Kazan)

The collected data demonstrate that, despite a large amount of information available to the public, there are still a lot of myths around HIV that lead to discrimination and stigmatisation of HIV-positive people. Moreover, they often impede the effective control of the spread of HIV infection. These myths are based on stereotypes, outdated information and fears. As a rule, they concern ways of transmission of the infection, the standard of living with HIV, as well as groups of people that are at risk of getting infected. It is important to reiterate that all of the aforementioned facts have a strong impact on people's self-perception and often lead to self-stigmatisation. In this case, the HIV status is viewed as something shameful and embarrassing; it ceases to be considered a disease, starting to be seen as a stigma:

I work at the AIDS Centre, I talk to women mostly, and some people do not even say the phrase 'HIV infection', they say 'Well, I have this ...' I really see that if she is denied services, she will not even complain to anyone. (Ksenia, female, 33 y.o., St.Petersburg)

According to an HIV activist, HIV-positive children in one of the orphanages where she conducted trainings, called themselves 'HIVed' (Russian 'vichyovye'): 'we are HIVed.' Only after the training, they began to say: 'Living with HIV' (Field Diary, 10 April 2017, Kazan). Adults living with HIV can limit the range of their communication to HIV-positive people, accepting the stigma:

A. said that she once again broke up with a man, who left after he learned that she had HIV ('everyone leaves'). She said that she was not going to try to build a relationship with an HIV-negative person anymore, but only with HIV-positive people. (Field Diary, 5 March 2017, Kazan)

In addition, it should be noted that activists and HIV-positive people also face the problem of double and triple stigmatisation, e.g. if they belong to such groups as drug users, MSM, sex workers, LGBTQ+:

Well, who is stigmatised? There is a stigma in the stigma now. Everyone without exception is stigmatised, there is a stigma in the stigma, one group stigmatised another, there is internal homophobia, external homophobia, heterophobia, male gays are afraid of lesbians, lesbians are afraid of homosexual men, everyone is afraid of transgender persons, transgender persons are afraid of everyone, heterosexuals stigmatise everyone with no exception, the patriarchal society stigmatises everyone. Well, cross discrimination and stigmatisation is what we experience now. (Alex, male, 29 y.o., St. Petersburg).

In this situation, a lot of HIV activists face the problem of ‘opening up about their identity’, as they see the need for this action as a political act to overcome discrimination. Some people do it boldly, but many are still afraid of being stigmatised and discriminated:

Well, just when we have several people who live openly with their status and talk about it on television, on the radio, everyone already knows them really, and they know that there are, say, 5 people or if there are 15 of them, then it will be..., if there are 50 of them. However, I myself am not ready to reveal my own status, but, as I say, I am fighting underground. (Alice, female, 35 y.o., St. Petersburg)

The state's discourse, which moralises the HIV epidemic, and the insufficient information policy contribute to the stigma and discrimination of HIV-positive people in medical institutions, the labour market and interpersonal communication.

### ***3.2 Structure of the HIV activism field***

A number of governmental and non-governmental organisations operate in St. Petersburg and Tatarstan in the area of HIV prevention, treatment and support of the rights of HIV-positive people. As for the state institutions, the key ones are the State St. Petersburg AIDS Centre and the Republican AIDS Centre in Kazan, which unite all organisations around them, because clients of any initiative eventually meet at the AIDS Centres. This is primarily because it is there and only there that you can get the necessary medications, after the second confirmatory test for HIV. In addition, the AIDS Centres also conduct various activities aimed at medical professionals, as well as informational and psychological support for people. In addition, St. Petersburg has a number of state infectious disease hospitals and addiction treatment facilities which treat HIV-positive people. However, despite cooperation and respect for the activities of the AIDS Centres, activists point out that their work is not enough; therefore, civil initiatives are important elements of prevention and combating HIV/AIDS. For example, Alex, 29, says:

As far as I know, clinicians do not have resources now for all the necessary services, in particular, psychological help and support, self-help groups, some deeper consultations. It is caused by their high workload, the lack of such specialists, or their lack of competence and skills. Well, for example, few employees of the AIDS Centre know how to talk with LGBT and transgender people, just because they have never met them. But we do, so we do it. What is the role of NGOs? Well, it's significant. It's easier and simpler with us, with the help of NGOs everything is faster; it's faster to get a diagnosis, get treatment, help, to re-socialise, adapt, and do other important things. (Alex, male, 29 y.o., St. Petersburg).

In total, in St. Petersburg, there are eight non-governmental initiatives in the field of HIV. Some of them are formally registered NGOs, some are parts of projects within NGOs that focus on other problems, some are network and actions groups. In Tatarstan, small communities of HIV activists exist, and they are active: the Svetlana Isambaeva Foundation and its mutual support groups of HIV-positive teenagers and women; the public organisation Prevention and Initiative (the low-threshold centre Ostrov); and the Timur Islamov Foundation. Formal registration allows initiatives to obtain a legitimate status for interaction with state institutions, apply for grants from the government, but makes them dependent on state control and policy. The lack of official registration provides the opportunity for more autonomous work, but significantly reduces resources for funding. Therefore, initiatives that focus on individual work with people, including outreach, peer counselling, support and testing, prefer to have a formal status, as it provides them

access to public medical institutions, a possibility to obtain permission for outreach buses, etc. Meanwhile, initiatives that are aimed at critical analysis and community monitoring of public policies and practices in the field of HIV prevention and treatment prefer to work as unregistered network patient groups, thereby minimising the risks of state pressure and persecution.

HIV activists involve different groups in their activities. Initiatives focus on drug users, sex workers, HIV-positive women, gay people and men who have sex with men, and overall, HIV-positive people and the general population. At the same time, these initiatives are aimed both at taking care of and supporting HIV-positive people in each group and at transforming the institutional and cultural order in society to ensure the protection of rights of the HIV community and vulnerable groups.

Specialisation of various initiatives makes it possible to minimise competition and internal conflicts. Despite the fact that leaders of initiatives point out some competition between organisations in the struggle for resources and influence at the state level, common activists emphasise stable horizontal cooperation between initiatives; moreover, sometimes they work in different organisations simultaneously.

Through work and inclusion of different groups, heterogeneity of the community develops it as an open community, sensitive to the problems and specific situations of people with different experiences. Even having their own focus in their work, initiatives automatically take agendas relevant to others into consideration.

The structure of the HIV activism field in St. Petersburg and Tatarstan at the moment is formed by stable NGOs and initiatives. Personal experience of civic activism in the HIV field over the past 20 years and that of others allows initiatives to choose different organisational forms that give them the opportunity to work in the existing political and institutional context; from formally registered NGOs to unofficial network communities. The focus of their work on different groups creates a heterogeneous, reflexive and sensitive community, with horizontal relations and cooperation, despite some competition due to funding shortages and strict state control over civil initiatives.

### ***3.3 Involvement in the work of initiatives, development of agency of participants and constituting of a community***

Those who get involved in HIV activism and come to work for NGOs and independent initiatives are, first of all, HIV-positive people or people whose friends or relatives are HIV-positive, as well as representatives of groups that NGOs work with:

HIV activism, how did I start? Well, I got a positive result, I mean the result of the HIV test, I'm HIV-positive, and a friend of mine invited me to work for this organisation, saying that they are starting a project, and I got here like that. However, there was an interesting case, I had a boyfriend who was HIV-positive, well, this was why I got tested myself; and when I had an HIV-positive boyfriend, I already thought that I should engage in HIV activism, because the problem was close to me, in reality, it touched me, too. (Igor, male, 22 y.o., St. Petersburg).

This, on the one hand, includes people who have experience of living with such a stigma, like HIV or, for example, drug addiction, homosexuality or sex work, which means that they know from personal experience the problems and difficulties faced by community members in their everyday

lives. On the other hand, it makes it possible to develop the community itself, involving its members in this work. Alex says:

Outreach work is off limits if you do not belong to the community; if this is the case, then unfortunately, this is not for you. And this is an essential method of conducting the preventive service. It means that an expert is not hired and sent to the community, but he/she is hired in the community and made an expert later. In this way, they develop the leadership potential of members of the community, as well as their skills and knowledge, so that they themselves would share and spread them. (Alex, m., 29 y.o., St. Petersburg)

Often, young people who turn to civic activism do not have any special education, and they receive the necessary skills when joining the team, attending special trainings and seminars, and gathering information by themselves. Education and professionalisation are becoming one of the key activities of organisations, which is not only the training of personnel for working in the HIV/AIDS environment, but also a resource for destigmatisation. For example, Vera, 36 y.o., says:

I saw how people grew up and became talented stars in helping people. And I saw how fates change, that is, how newly released former drug addicts come to this field, and years later, these people, who might be called scum, (well, this also applies to me at some moment of my life), how these people communicate, for example, with representatives of the Ministry of Healthcare or authorities in Moscow, I mean how they look and feel wearing suits, when they express their point and provide arguments and believe in them. They do not act for commercial purposes. And they represent so many lives, and it impressed me a lot. (Vera, female, 36 y.o., St. Petersburg)

In organisations, newcomers take a variety of positions: case managers, project coordinators, peer consultants and outreach workers. From the community's point of view, for these positions, the HIV status itself is the key criterion, and its absence can be a serious obstacle not only to providing peer counselling, but also to simply providing psychological support.

At the same time, along with the 'line'/field staff, who deal with ongoing interactions with clients, target groups and the population as a whole, there is also a number of professional workers in NGOs, usually psychologists, lawyers, analysts and experienced managers. Their hiring and involvement are determined not by their HIV status, but by their professional knowledge and competences.

However, regardless of what position a person is applying for/is hired for, tolerance and acceptance of different identities, lifestyles and experiences is one of the key criteria for being involved in a particular team and work as a whole. Julia, 34, project coordinator, says, 'If there is a fear that a person can cause harm to one of the clients, it does not matter in which programme, then we will not involve this person in any work.' (Julia, female, 34 y.o., St. Petersburg)

The role of tolerance, positive HIV status and belonging to target groups is so important as it is related to guaranteeing anonymity and the creation of a safe space for both activists and their clients:

... the issue here is also that we have a specific audience. For example, let's say, in a small bus that works with sex workers, in general, well, the attitude to outsiders is very

suspicious. Girls don't trust them, they feel uncomfortable. Drug users are also a discriminated group, which is, in fact, outlawed, too, so when they see some fresh faces... and volunteers are here today, but tomorrow they are gone... (Julia, female, 34 y.o., St. Petersburg)

Therefore, the field of HIV activism is quite closed in its structure, and daily activities of organisations and activities rarely include random, outside people, and usually do not involve the work of volunteers, who are exclusively engaged in participation in large-scale events. It is worth noting that part of the volunteer work is carried out by activists themselves, who get payment within one particular area and perform some additional functions without payment.

Simultaneously, a long time in the field of HIV activism and participation in various activities allows its participants to accumulate social capital and acquire high status in the eyes of other activists. For example, for many novice HIV activists the personalities of heads of organisations are role models and a source of strength and inspiration (as a rule, heads of these NGOs and initiatives are those who have the longest experience of field work and who are recognised as experts). This, in its turn, leaves a mark on the organisation and perception of the hierarchy within the initiatives; despite the fact that hierarchy exists and is established by both the structural organisation of NGOs (executives, coordinators/managers/rank and file employees), which determines work areas and responsibility, and the symbolic capitals of recognition and authority among members of the field, on the whole, activists emphasise the democratic way of work in a team and a family atmosphere in the teams.

Thus, NGOs and initiatives working in the HIV space not only set the structure of HIV activism field, but also shape, support and develop the community. This happens, first of all, through the targeted recruitment of community representatives. Secondly, through their education and development as workers, activists and key actors in the HIV space. Thirdly, such professionalisation of community representatives in NGOs makes it possible to create comfortable and safe communication, environment and projects for ordinary members of different groups within the HIV community.

### ***3.4 Collective actions and their effect***

NGOs and associations implement various types of activities aimed at addressing the problems topical for the HIV community. Informants note an extremely low level of competence among the population in Russia in issues related to HIV, which, in turn, leads to the creation of strong myths concerning HIV infection, pathologisation and stigmatisation of HIV-positive people. Fighting against institutional discrimination, activists hold special conferences, training seminars for representatives of medical, educational, and social institutions. They also work with people in order to inform them and prevent HIV. This is done by using mobile buses, providing the opportunity of obtaining counselling and anonymous testing in the city (see Plate 2).



Plate 2. Campaign for HIV testing and distribution of leaflets and condoms.

A special area of activity of HIV activists is educational work with young people in vocational schools and universities (see Plate 3). Due to the virtual state ban on sex education in Russian schools, adolescents and young people demonstrate an extremely low level of competence not only with regard to HIV/AIDS, but also sexuality and health in general.



Plate 3. A 'training' on HIV in Kazan Theatre School (participants gave permission to be photographed).

One of the key problems for the community is availability of medicine and access to treatment for HIV-positive people. Activists problematise not only the regularly occurring shortage of medicines, but the 'quality-price' ratio of the supplied and used drugs. They also emphasise the obsolescence of the current treatment regimens in comparison to modern Western HIV therapy practices, the intention to save funds when procuring quality medicines, and price manipulation in the pharmaceutical market. Direct actions, used in the past, which were actually quite effective, aimed at drawing attention to problems of treatment have become too risky due to the increased legislative pressure on public events. Therefore, the emphasis in the struggle for the availability of medicine in St. Petersburg is put on expert work; monitoring of procurement of and prices for medicines, as well as work in the field of intellectual property, which provide a complete picture of how many people get medicines, whether they are bought for the best price or the price is too high, and how their price can be reduced. Analytical activity allows activists to provide expert information, to act on an equal footing with state and multinational organisations, to criticise, and thereby attract attention to problems.

In order to minimise the negative consequences of medicine shortages, activists in St. Petersburg and Tatarstan have created special 'first aid kits'. They include medicines that are leftover when, for example, patients change their treatment regimens. When someone does not get medication, then he or she has the opportunity to get it from this 'first aid kit':

I was in a situation when we called and there was no medicine... And a person only has 72 hours. So what can we do? We had to do everything on our own. I mean, we have a large first aid kit, yes ... Everything had to be found somewhere among patients. Because still medicines pile up, regimens change, there are drugs leftover, or someone dies. And so they bring them, yes ... Since pills cannot be returned to the pharmacy. Well, and we do it to have something to help people with. Some people lose their stuff. Yesterday a guy came, he moved house, and he had had the same therapy for five years. He says, 'Damn it, I moved from one apartment to another and put the medicines in some packet and lost them. And where they are now I do not know.' He hadn't had any medication for 25 days. I say, 'Well, of course, we'll help you now.' Soon we found everything. All by ourselves. (Arthur, Kazan)

In addition, activists in both locations are actively working in the community at the individual level in order to encourage accepting HIV infection as a disease that does not reduce the quality of life, is not socially dangerous and does not carry a moral value. For this purpose, support groups are organised, and psychological counselling is provided.

One of the characteristics of HIV activism in Tatarstan is the participation of HIV-positive teenagers in it. The mutual support group of teenagers in Kazan is unique, because, to our knowledge, only in Nizhny Novgorod and Yekaterinburg are there similar groups, and they do not exist in other regions. The mutual support group of teenagers with HIV was created by the HIV activist Svetlana Izambaeva. The uniqueness of the group is that its participants are not only HIV-positive teenagers but also their friends. During the period of participant observation, from February to May 2017, the support group had meetings once a week, and at weekends (see Plate 4).

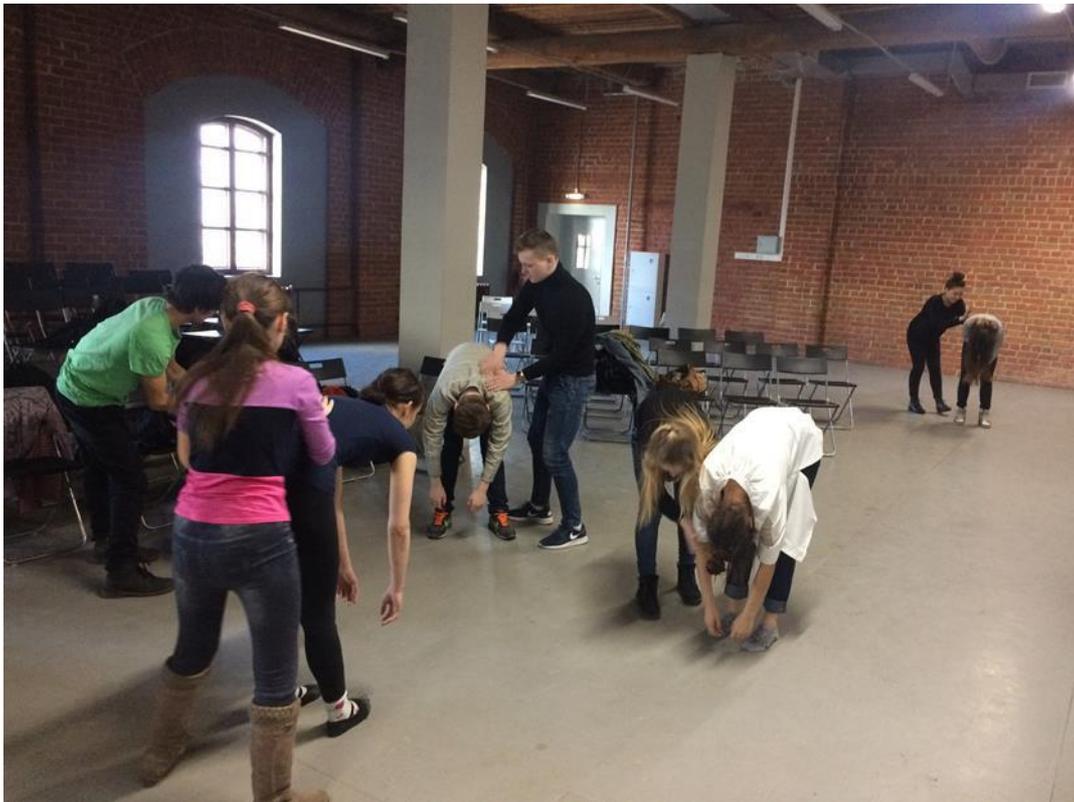


Plate 4. A 'theatre training' in the mutual support group for teenagers (at the Smena Centre of Modern Culture, Kazan)

An important part of this area of work is support, which helps those who for some reason stopped taking medication, to start taking it again, and to people who have just learned about their status to get all the necessary information and medical support.

It can be physical accompanying or remote supervision. That is, I can ... I already did so, once, yes, I can get a person to phone someone. It's not difficult for me. If there is someone for whom this is their first time, we can get a person to phone, without meeting with them or having a physical contact, but in fact it is simple. For example: 'Hello, you need to go there, and then there. When you get there, call me, please.' Why is this necessary? 'If you come across this or that problem, call me, I will tell you how to solve it, if it is possible.' I had such a situation, when a person got to the Centre, he stood at the reception and did not understand what to do. He turned the speaker phone on so that I could talk to the receptionist and explain what he, this person, wanted. To do this I didn't have to go or be present there. You can supervise a person remotely. (Alena, female, 38 y.o., St. Petersburg)

In addition to such individual psychological support, some organisations which usually work closely with the LGBTQ+ community, create a space where HIV-positive people can get acquainted with each other and spend time together, where among 'peer' HIV-positive people, this characteristic is not taken into account. For this purpose, regular movie nights, meetings, board games nights and other leisure activities are organised.

However, activists often disagree in assessing the effectiveness of their activities. The difference is particularly visible between those who have long been in the field and activists who have joined recently. The former tend to give a higher assessment of the effectiveness of organisations, which

is due to the availability of their experience of the first stages of HIV activism and a more complete awareness of the work done. For instance, Olesya, a 32-year-old activist, says:

Well, while activists are alive, something is changing, one way or another, you know. I think it's getting better each year. I have been living with the status of an HIV-positive person for eleven years. And since those days when I just found out about my status and to this point, it's been eleven years now. And it seems to me that a lot has changed. Attitude, well, not of the whole society, but most people have a more reasonable attitude. People have become more attentive to this. Doctors have also become more reasonable. Well, there is less discrimination. (Olesya, female, 32 y.o., St. Petersburg)

However, younger activists and those who have lower positions often emphasise that although organisations do a great job, in comparison to the scale of the disease, in general, it is only a drop in the ocean, which obviously cannot be enough, and that it is necessary to work more.

Nevertheless, active involvement in the work often leads, according to activists, to emotional burnout. This is due to the close communication with different people and institutions during a day, which requires strong emotional work, and with the impossibility of seeing the results of your activity in the short term.

One of the key ways to overcome burnout and fatigue, along with specially organised psychotherapeutic support of employees within the NGO, is 'return to the community': provision of direct services. This is especially important for those activists whose main work objectives are in other areas. Personal consultations and support allow activists to interact directly with those at whom their activities are directed, which helps to see the results of one's activities here and now. Julia explains:

Because there is work which is like compulsory, but there is also work for pleasure; that probably can be called a hobby, because it is, well, counselling people, support ... some, I do not know, there is protection of rights, in general if somewhere something comes up related to my area of expertise, I enjoy doing it. (Julia, female, 34 y.o.)

In other words, activists emphasise that working with the community, within the community and for the community, are the main ways to protect and promote the rights of HIV-positive people and HIV prevention. Egor, an activist with a lot of experience, points out:

This is exactly field advocacy, with real patients, it was still more effective, so I believe, and it remains the main mechanism. I always want to achieve more – get on various committees to take some decisions, do something else, but practice shows that these committees don't do anything crucial, that it's usually just reports, some showy events, while just a simple protest or attracting a patient's attention, a press conference, a round table in the region with everyone who deals with the HIV problem, that's what works better. (Egor, male, 38 y.o.)

Thus, through various types of activities (from analytical monitoring of public procurement to accompanying people in a difficult life situation to the AIDS Center), NGOs work and support the community, and the community, in turn, is a supportive environment for activists, giving them a sense of belonging and importance of their own activities and lives.

## 4. Conclusions

The study of HIV activism in St. Petersburg and Kazan/Tatarstan shows that with the rapid growth of the HIV epidemic in Russia, which affects all population groups, the life of HIV-positive people and activists' work takes place, on the one hand, in the context of the high level of stigmatisation of HIV-positive people. On the other hand, there is strict restriction and control over the actions of civil society, which are set by the political agenda in Russia. Low competence of the population (including medical professionals) in the issues of transmission, the standard of living with HIV and population groups that can/cannot be infected, the moralising discourse of the state and ineffective state policy construe HIV as a moral stigma, leading to discrimination, social inclusion, and self-stigmatisation of HIV-positive people. However, both in St. Petersburg and Tatarstan, a heterogeneous but solidary HIV activist space is developing, aimed both at supporting and caring for the community and at trying to transform the institutional regime with regard to HIV.

The structure of the HIV activism field is set by officially registered NGOs and informal network associations. The choice of a specific form of organisation is determined by the direction of its activity. Initiatives that are oriented toward individual work with people prefer to have a formal status, which gives them the opportunity to legitimately interact with state structures, although it puts them under strict state control. Those initiatives that are aimed at critical analysis and control of the state policy and practice in the field of HIV prevention and treatment prefer to work as unregistered network patient groups, thus, minimising the risks of state pressure and persecution, but also narrowing opportunities for funding and representation in the public space.

NGOs and initiatives, first of all, involve representatives of the community in their work, contributing to personal destigmatisation, social inclusion and development of their agency. Although NGOs recruiting members of the community, which 'precisely because they are integral members of the community, they have been exposed to the same social and cultural memes, which often means that they are constrained by the very patterns of thinking, being and doing that they are attempting to change' (Wood, 2017: 687), in this case NGOs overcome this problem by continuous professionalisation of the staff, by using various resources: their own capital, educational programmes, inviting external specialists, and engagement in international networks. In general, the core of the HIV community in St. Petersburg and Tatarstan is formed as a highly professional and expert environment.

Being key figures in the community, activists create a comfortable and safe environment for various groups of people with HIV, including those experiencing multiple stigmatisation: drug addicts, sex workers, LGBTQ+, MSM, etc. However, acceptance of the diversity of experiences and identities within the community and high reflexivity to various types of vulnerability, stigmatisation and discrimination do not yet lead to destigmatisation of these groups in society and openness of the community as a whole to the outside world. This prevents HIV activists uniting with other civil initiatives, volunteers and social movements, although, as McCrea and colleagues emphasise, reflexive solidarity between different communities and social movements is one of the key ways to combat social injustice (McCrea *et al.*, 2017: 400).

The activity of NGOs focuses on solving the problems faced by the HIV community and consists of various areas of work, including those at the state and international levels. However, for activists, the key activity is work within the community and for the community: improving the quality of life of HIV-positive people here and now. Activists organise support groups, individual counselling and

support, outreach work, provide medicines in emergency situations, etc. Moreover, direct communication and assistance to HIV-positive people gives employees of civil initiatives a sense of the meaning and importance of their work. Thus, the emerging HIV community is becoming, in a sense, a communication space (Souza, 2009), which is important for both activists and community members in maintaining their identity, recognition and belonging.

## 5. Future analysis

Further research and analysis of clusters might include:

- A more detailed elaboration of the concepts of ‘activism’ and ‘activist’ and their correlation with the concept of public arena operatives proposed by Stephen Hilgartner and Charles Bosk (Hilgartner and Bosk, 1988).
- Identifying the boundaries of the concepts of activism/activist within communities. This question arises, for instance, in the case of HIV activists who call themselves activists, despite the fact that, for some of them, participation in the movement against the HIV/AIDS epidemic has become a profession, their main occupation and a source of livelihood.
- Analysis of the repertoires of action and constitution of solidarity, similarities and differences, by activism fields aimed at the inclusion of some (stigmatised) groups in the community and oriented towards public protest.
- Analysis of destigmatisation strategies. In the case of HIV activism, it can be seen that professionalisation in the activism field is one of the key strategies of destigmatisation. Informants successful in other professional fields often overcome self-stigmatisation only after becoming activists and after professionalisation in activism.

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## Appendix 1: Table of respondents' socio-demographic data (St. Petersburg)

Pseudonym	Gender	Age	Education	Employment	Residential status	Family status	Country of birth
Alice	Female	35	General Secondary Education	Work	Lives independently with own partner	Married	Russia
Vera	Female	36	No information	Work	Lives independently alone	Single	Russia
Sacha	Male	51	No information	Does not work	Lives independently alone	Single	Russia
Petr	Male	39	Higher Education	Work	Lives independently with own partner	Living with partner	Russia
Misha	Male	47	Higher Education	Work	Lives independently alone	Single	Russia
Kirill	Male	19	General Secondary Education	Student, Work	Now information	Single	Russia
Julia	Female	34	No information	Work	Now information	Now information	Russia
Egor	Male	38	Professional Secondary Education	Work	Now information	Now information	Russia
Igor	Male	22	General Secondary Education	Student, Work	Lives independently alone	Single	Russia
Alex	Male	29	General Secondary Education	Work	Lives independently alone	Single	Russia
Ivan	Male	29	Higher Education	Work	Lives independently alone	Single	Russia
Ekaterina	Female	31	Higher Education	Work	Lives independently with own partner	Living with partner	
Alena	Female	38	No information	Work	Lives independently with own children	Divorced	Russia
Olesya	Female	32	Specialized Secondary Education	Work	Lives independently with own partner and children	Living with partner	--
Arina	Female	22	General Secondary Education	Student, Work	Lives independently alone	Single	Russia
Roman	Male	27	Higher Education	Work	Lives independently alone	Single	Russia

Olga	Female	31	Higher Education	Work	Lives independently with own partner and children	Married	----
Eugenii	Male	36	Higher Education	Work	Lives independently with own partner and children	Married	Russia
Ksenia	Female	33	General Secondary Education	Work	Lives independently with own new partner and children	Divorced	Russia

## Appendix 2: Table of respondents' socio-demographic data (Kazan)

Pseudonym	Gender	Age	Education	Employment	Residential status	Family status	Country of birth
Renata	Female	32	Higher education	Work	Lives independently with own partner and child	Married	Russia
Alyona	Female	36	Higher education	Work	Lives independently with own partner, brothers and children	Married	Russia
Natalia	Female	19	Special secondary education	Does not work	Lives with parents	Single	Russia
Anatoliy	Male	21	Undergraduate - special secondary education	Work	Lives independently with sister	Single	Russia
Anastasiya	Female	21	Secondary Education	Part time work	Lives independently	Single	Hungary
Ruslan	Male	40	Higher education	Work	Lives independently with own partner and children	Married	Russia
Rustem	Male	17	Undergraduate - special secondary education	Part time work	Lives with grandmother	Single	Russia
Alexander	Male	41	Higher education	Work	Lives independently with own partner and children	Married	Russia
Artur	Male	38	Special secondary education	Work	Lives independently with own partner and children	Married	Russia
Dina	Female	43	Special secondary education	Work	Lives independently with own partner and children	Married	Russia