

# Systemic barriers accessing HIV treatment among people who inject drugs in Russia: a qualitative study

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Achieving ‘universal access’ to antiretroviral HIV treatment (ART) in lower income and transitional settings is a global target. Yet, access to ART is shaped by local social condition and is by no means universal. Qualitative studies are ideally suited to describing how access to ART is socially situated. We explored systemic barriers to accessing ART among people who inject drugs (PWID) in a Russian city (Ekaterinburg) with a large burden of HIV treatment demand. We undertook 42 in-depth qualitative interviews with people living with HIV with current or recent experience of injecting drug use. Accounts were analysed thematically, and supplemented here with an illustrative case study. Three core themes were identified: ‘labyrinthine bureaucracy’ governing access to ART; a ‘system Catch 22’ created by an expectation that access to ART was conditional upon treated drug use in a setting of limited drug treatment opportunity; and ‘system verticalization’, where a lack of integration across HIV, tuberculosis (TB) and drug treatment compromised access to ART. Taken together, we find that systemic factors play a key role in shaping access to ART with the potential adverse effects of reproducing treatment initiation delay and disengagement from treatment. We argue that meso-level systemic factors affecting access to ART for PWID interact with wider macro-level structural forces, including those related to drug treatment policy and the social marginalization of PWID. We note the urgent need for systemic and structural changes to improve access to ART for PWID in this setting, including to simplify bureaucratic procedures, foster integrated HIV, TB and drug treatment services, and advocate for drug treatment policy reform.

**Keywords** Russia, HIV/AIDS, antiretroviral treatment, people who inject drugs, qualitative study, health systems

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## KEY MESSAGES

- Access to HIV treatment is inevitably a product of its social context, with systemic factors playing a key role in reproducing treatment initiation delay among people who inject drugs
- Qualitative interview accounts with people who inject drugs identified three core systemic barriers to HIV treatment access: labyrinthine bureaucracy; an expectation that access to HIV treatment was contingent upon treated drug use in a setting of limited drug treatment opportunity; and vertically organised treatment delivery systems for HIV, drug use and TB.
- Structural interventions are needed to: simplify bureaucratic procedures regulating treatment access; enhance patient treatment literacy; foster integrated HIV, TB and drug treatment; and advocate for policy reforms to drug treatment provision.

## Introduction

The scale-up of antiretroviral treatment (ART) has been made possible through massive international investment in combination with health system changes at the local level. These transformations are driven also by the global pledge to achieve ‘near universal access’ to ART for all those in need (United Nations 2006). Yet, access to ART remains highly variable. In the five nations (China, Malaysia, Russia, Ukraine and Vietnam), which host nearly half of all global HIV cases among people who inject drugs (PWID), PWID account for 67% of cumulative HIV cases but only 25% of those accessing ART (Wolfe *et al.* 2010). In Eastern Europe, where there is a large burden of HIV linked to drug injecting, PWID are also disproportionately affected by problems accessing ART (Bobrova *et al.* 2007; Donoghoe *et al.* 2007). According to official estimates, access to ART in Russia has increased from a coverage around 1% of those in need in 2005 to over 50% in 2011 (Parfitt 2011). Official statements make claim to ‘universal access’ having been achieved (Parfitt 2011). Yet, while an estimated 80% of HIV cases in Russia are among PWID, ~20% of those receiving ART are PWID (Foundation for Intersectoral Partnership 2009). Even in settings where considerable transformations in the delivery of ART have been achieved, access to ART is shaped by social and material inequalities and is most problematic among the socially marginalized (Biehl 2007; Cataldo 2008).

### The social context of ART access

In recognizing access to ART as a product of social condition, there have been recent calls to assess the ‘risk environments’ of HIV treatment delivery. Recent reviews highlight an interplay of environmental factors (Krusi *et al.* 2010; Wolfe *et al.* 2010), including ‘macro-level structural factors’, such as the adverse impacts of criminalization, law enforcement dominated drug policies, and a lack of political and financial investment in treatment and care for PWID; and ‘meso-level systemic factors’, such as lack of physician education about substance use, low-threshold access to opioid substitution treatment (OST), directly administered antiretroviral therapy, tailored adherence support interventions, and integration across HIV, tuberculosis (TB) and drug treatment services. The provision of OST in particular enhances ART access, adherence and clinical outcome among PWID (Wood *et al.* 2005; Lucas *et al.* 2006; Roux *et al.* 2009; Uhlmann *et al.* 2010), while health systems which foster integrated approaches towards harm reduction show promise

(Altice *et al.* 2007; Sylla *et al.* 2007; Havlir *et al.* 2008; Lambers *et al.* 2012).

It is important to note that ‘systemic factors’ affecting treatment access—that is, organizational structures and processes, service management and delivery, treatment policy, resourcing (Melgaard *et al.* 1998)—are themselves situated by their social and historical contexts. The legacy of the Soviet health system, for instance, shapes how systemic factors have contemporary effects, including in the development of responses to HIV, TB and drug use. For instance, the disease-specific approach and vertical structure of the health system (Dimitrova *et al.* 2006; Taktchenko-Schmidt *et al.* 2010), and the history of opposition in narcology to internationally recommended OST, both impact heavily upon HIV-related service provision (Elovich and Drucker 2008; Rhodes *et al.* 2010). Health system practices are shaped by, as well as reproduce, the effects of wider structural forces, which not only include macro-level policies and investments in relation to health but also surrounding cultural values regarding health and care, and importantly, the populations affected. Systems governing treatment access and delivery thus reify their social contexts, ‘reproducing their effects in the micro social environment’. The adverse social effects of ART access and delivery systems for PWID may include, for example, the reproduction of treatment initiation delay, felt stigma and discrimination, and disengagement from treatment services (Biehl 2007; Wolfe 2007; Krusi *et al.* 2010). Qualitative research illustrates how the HIV treatment access experience may reproduce internalized stigma among marginalized populations, linked to treatment rationing practices as well as to perceptions of relative deservedness to state funded care (Biehl 2007; Bernays *et al.* 2010).

### The case study context

We draw here on a qualitative case study of HIV treatment access among PWID in the city of Ekaterinburg, the capital of Sverdlovsk region in the Russian Federation. With a population of 1.34 million, Ekaterinburg is a major industrial and cultural hub. The Sverdlovsk region was one of the first Russian provinces affected by HIV, with 47 988 registered cases by the end of 2010. The prevalence of HIV in the general population in Ekaterinburg is twice the Russian average, and reaches 64% among PWID (UNAIDS 2006).

Regional estimates in 2010 showed 8793 registered patients to be in need of ART by the end of 2010, with 8167 (93%) receiving it. These estimates, however, underestimate ART need

among PWID as they do not capture those not registered to services. The region had registered 6224 HIV-related deaths by the end of 2010, of which 31% were registered as deaths from AIDS and 15% from TB. The delivery of ART has expanded dramatically since 2005. The regional AIDS Centre has made major efforts towards achieving universal access to ART, including providing integrated psychological, social work and harm reduction services. The Centre provides premises for an HIV support group and for Narcotics Anonymous.

## Methods

Between November 2009 and June 2010, we conducted in-depth qualitative interviews in the Russian city of Ekaterinburg with 42 people living with HIV who had current or recent experience of injecting drug use. Interviews sought to generate participant accounts of the lived experience of accessing treatments for ART, TB and drug dependence (see also Rhodes and Sarang 2012).

### Sampling

Participants were recruited by chain referral through social networks of PWID, facilitated by introductions from 'Chance+', a local non-government organization (NGO) delivering harm reduction and support services for PWID. Sampling adopted a purposive approach, in relation to gender, age, ART and drug treatment service contact, elapsed time since HIV diagnosis, and presence of TB co-infection. Coding of data guided sampling strategy theoretically in relation to key emerging themes.

### Interviews

Data were generated via qualitative interviews, facilitated by a topic guide. Interviews were undertaken by A.S. and trained qualitative fieldworkers supervised by A.S. and T.R. They were loosely structured and designed to generate participant-led accounts. Interviews were audio-recorded with informed consent, lasting between 30 and 90 min. They were conducted outside of health services with the exception of four which were conducted in a TB clinic.

### Analysis

Interviews were transcribed verbatim, translated into English, coded initially for emerging core descriptive content, with coding further refined in an iterative process of data coding, charting and interpretation, assisted by MaxQDA10 software. We identified three core themes linked to the category of 'systemic barriers' to ART access which cross-cut accounts: 'labyrinthine bureaucracy', 'system Catch 22'<sup>1</sup> and 'system verticalization'. We outline these below. We begin this analysis by offering a brief case study which is both typical and captures how the core themes relating to systemic barriers to ART interplay to make up a lived experience. Core data on sample characteristics were collected in response to structured questions as well as extracted from transcripts.

### Sample characteristics

The sample comprised 34 people who were currently injecting (i.e. in the past 30 days) and 8 people who said that they had stopped (Table 1).<sup>2</sup> The average age of the sample was 29 years (range 25–48 years) and predominately male (26; 60%). Heroin was the drug of choice for all of those currently injecting. Half had children and 44% (19) were unemployed. The median time since HIV diagnosis was 5.5 years (range 0–10). Most (36; 84%) had checked their immune status (IS) at least once, and of these ( $n = 36$ ), 69% (25) reported their last IS as  $\leq 350$  CD4, and 22% (7) reported their last IS as  $\leq 100$  CD4. The World Health Organization currently recommends initiation of ART at a CD4 threshold of 350 cells/mm regardless of symptoms. Approximately one-third (16; 37%) were receiving ART at the time of the interview, and 47% (20) reported ever having received ART. Of these ( $n = 20$ ), approximately one-third (7; 35%) reported adherence problems. Seven (16%) reported having had TB. One-half (21) had previous experience of drug treatment. The majority (25; 78%) had experienced imprisonment.

### Ethics

The study had ethical approval from the London School of Hygiene and Tropical Medicine Ethics Committee, national approval from the Ministry of Health of the Russian Federation and regional approval from the Ministry of Health of Sverdlovsk Oblast. Anonymous participation was conditional upon written informed consent. Participants received reimbursement to the non-cash equivalent of \$17 via telephone cards, coffee and snacks. Participants were also provided with a pack of sterile needles/syringes, condoms and referral information. Participants who spoke of transport problems as a determining factor in their access to ART were offered help with transportation as well as facilitated referral to an HIV specialist and psychologist. Participant names are pseudonyms with the exception of one who preferred to be named (Table 1).

### Findings

We begin our analysis with a case study illustrating how the experience of HIV treatment access is situated in a context of interplaying systemic and structural factors. We then outline three cross-cutting themes in participant accounts: 'labyrinthine bureaucracy', 'system Catch 22' and 'system verticalization'.

#### *Nadya and Oleg: living and dying with HIV*

This is how Nadya recounts what happened to her husband, Oleg:

My husband died this year, because of AIDS. He was 30 years old; one of the first patients registered with the AIDS Centre. When he went there he was told 'You should quit drugs, and then come back to us'. They told him to go and get treated for drugs. He stood up and went away.

This description is typical of many we interviewed (Rhodes and Sarang 2012). Following his attempt to access ART, and the instruction of the AIDS Centre that he should find treatment for his drug addiction first, Oleg did not return to the clinic for

**Table 1** Sample characteristics

Pseudonym	Age	Injecting drug use	Years since HIV diagnosis	Ever positive HCV diagnosis	Ever TB diagnosis	Last CD4 count	ART treatment	Drug treatment	Experienced prison
Galina	28	Former	10	Yes	No	–	Never	Never	Yes
Vanya	38	Current	8	Yes	No	50	Currently	Never	Yes
Arkady	36	Current	2	Yes	No	100	Currently	Previously	No
Elena	35	Current	10	No	No	210	Never	Previously	Yes
Denis	31	Current	5	Yes	No	330	Never	Previously	Yes
Petya	38	Current	9	Yes	No	–	Never	Never	Yes
Lev	41	Current	8	No	No	100	Never	Previously	Yes
Fedor	29	Current	1	No	No	–	Never	Never	Yes
Lilyia	25	Current	8	Yes	No	46	Never	Never	No
Vadik	27	Former	9	Yes	No	160	Currently	Previously	No
Sergey	27	Current	4	Yes	No	419	Currently	Never	Yes
Polina	27	Former	0	No	No	200	Never	Never	No
Pasha	27	Current	4	Yes	No	350	Currently	Never	No
Oxana	39	Current	0	Yes	Yes	–	Never	Never	Yes
Sveta	30	Former	7	Yes	Yes	150	Currently	Never	No
Raisa	28	Current	7	Yes	No	640	Currently	Never	Yes
Tanya	27	Current	1	Yes	No	–	Never	Previously	No
Vlad	34	Current	1	Yes	No	360	Never	Previously	Yes
Maria	48	Current	1	Yes	No	240	Previously	Previously	No
Lada	33	Current	5	Yes	No	750	Never	Previously	No
Yuri	34	Current	2	Yes	Yes	200	Currently	Previously	Yes
Nadya	28	Current	1	Yes	No	900	Never	Previously	No
Katya	38	Current	9	Yes	No	300	Previously	Never	Yes
Misha	27	Current	1	Yes	No	200	Never	Previously	Yes
Ulyana	30	Current	9	Yes	Yes	600	Never	Previously	Yes
Lena	28	Current	6	Yes	No	–	Never	Never	No
Dima	34	Current	4	Yes	No	192	Currently	Previously	Yes
Vasily	27	Current	7	Yes	No	112	Never	Previously	Yes
Evgeniy	25	Former	6	Yes	No	680	Previously	Never	No
Inna	27	Former	5	Yes	Yes	66	Currently	Never	Yes
Maxim	27	Current	8	Yes	No	400	Never	Previously	No
Nikolai	30	Current	7	Yes	No	150	Never	Never	No
Matvei	29	Current	2	Yes	No	–	Never	Previously	Yes
Nina	25	Current	9	Yes	No	–	Never	Never	Yes
Timofei	34	Current	2	Yes	No	300	Never	Previously	Yes
Sasha	27	Current	3	Yes	No	40	Currently	Previously	Yes
Aleksei	25	Current	3	Yes	No	150	Currently	Previously	No
Olga	29	Current	10	Yes	No	290	Previously	Previously	Yes
Natasha	30	Current	8	Yes	No	210	Currently	Previously	No
Taisia	26	Current	7	Yes	No	311	Currently	Previously	No
Andrey	29	Former	10	Yes	Yes	56	Currently	Never	Yes
Oleg	39	Former	0	No	Yes	200	Currently	Never	No

Notes: HCV = hepatitis C.

another 9 years, by which time his illness had progressed to the late stage of AIDS. In the intervening years, Oleg had made numerous attempts to seek treatment for his drug use. He had sought help from the regional drug treatment dispensary and attempted self-detoxification. Below, Nadya describes his last

attempt at drug withdrawal, which coincided with the realization of how urgent his HIV treatment had become:

We went ‘cold-turkey’. I remember that he felt really bad during the first week of the withdrawal. We relapsed after a

week. I did my dose, and I felt normal. He did his, and he didn't even feel any better. Then we realised that the pain he was going through was not from withdrawal. We called the ambulance. They came, looked at him, and said 'He has AIDS'. They then turned back and left... It was obvious; he had lost weight, they asked for all his symptoms—'You use drugs?'—and they went away.

Nadya continues her story of the difficulties she and Oleg experienced in having the helping system respond in their time of crisis:

A doctor from the polyclinic came the next day. When she arrived, the first thing she said was: 'Because of this rubbish, because you guys shoot up, a whole generation has died. My son has died. You deserve to be beaten!'. That was it. She didn't prescribe any drugs or anything. She just had an attitude.

The following day, after help had been refused during the home visit, Nadya brought Oleg to the AIDS Centre. With the help of a social worker, they managed to make contact with an infectious disease doctor without a prior appointment, and Oleg was referred for IS tests and for TB screening. But Oleg died the next day.

After learning of her own HIV infection, Nadya sought guidance from the local NGO providing syringe exchange and other harm reduction services. Having lost her passport, and without proof of identity, she was initially unable to get an appointment with the AIDS Centre. With the help of the NGO, an appointment was nonetheless arranged, and unlike Oleg, Nadya currently attends the AIDS Centre for check-ups regularly. With an IS of ~900 cells, she is yet to start ART.

Like many we interviewed, Nadya perceives her drug dependency as an obstacle to HIV treatment access, and she therefore sees accessing treatment for her drug use as a priority. But she faces various challenges in navigating her way out of drug dependency. Nadya does not have an independent source of income, yet state narcological services are not delivered for free, and independent or commercial alternatives are more expensive. Oleg worked in a factory, and she now depends on her parents for what they can give her. Nadya is trained as a chef but is unable to work because of childcare. Keen to work towards stopping her drug use, Nadya, like many, sought help from the narcological services provided via the AIDS Centre. Help was not as forthcoming as she had hoped:

There is a narcologist [at the AIDS Center]. I thought I would come and check what is there. She had this conversation with me, found out everything—'How long do you shoot up?', 'What is your dose?', and so on... And then she says 'I can't help you!'. I'm, like 'Wow, I thought we have some hospitals here, or something, that could help me quit, can you help me somehow?'. And she says 'No. I cannot help you with anything. Quit yourself'.

The narcologist was able to refer Nadya to the regional hospital-based narcological services for detoxification. But these services are not provided anonymously, unless separately negotiated and paid for. Being state registered as an addict

carries with it various adverse consequences, such as difficulties accessing employment or obtaining a driving licence (Bobrova *et al.* 2006), and so Nadya, like many, elected not to register for treatment. Nadya's main concern was protecting her baby from being removed into state care:

I don't want to get registered with narcology! Why? To have check ups from the social services? I have a baby. And if they start to make a noise—A baby lives with a junkie!

With her parents' support, Nadya next tried a private residential rehabilitation centre in a neighbouring city. Most such services locally are faith based. For Nadya, this form of treatment did not work and she lasted 2 weeks. She felt it to be like 'some kind of sect', where 'people go crazy', religiously getting up at 6 am to 'start singing songs with a synthesizer', and otherwise 'watching disks from American sermons'.

The stories of Nadya and Oleg are not exceptional (Rhodes and Sarang 2012). Their stories plot the coming together of systemic and structural factors shaping the social conditionality of HIV treatment access. The three cross-cutting themes we present below resonate with the experiences of Nadya and Oleg.

#### *Labyrinthine bureaucracy*

The system of ART provision, and specifically the administrative process, was described as a byzantine set of pre-requisites that made navigating the system extremely complex. Treatment initiation required multiple appointments with different health specialists. We summarize here the process of treatment initiation at its most basic as described in participant accounts. First, an appointment is made in advance. In this setting, it is impossible to simply show up at a clinic or hospital and arrange to see a doctor. Rather, appointments are to be made by telephone. Many seeking HIV-related care are unaware of this. Unfortunately, the telephone line is often engaged:

To be tested for immune status, [one has to make] an appointment with the doctor. He needs to be registered for this appointment. Drug addicts, mainly those who haven't been coming to the [AIDS] Centre for years, don't know that they have to register. So people go there and they are asked if they have an appointment. When they say no, they are sent away. They are told to ring and make an appointment. And to make an appointment by phone is very complicated as it is very difficult to get through. (Vanya, 38 years)

The typical time elapsing between an initial telephone call and an appointment is around 1 month. At this initial appointment, the doctor provides referrals for tests for IS and viral load, general blood screening and bio chemistry, urine checks and fluorography. These tests are undertaken in separate cabinets, usually with queues to each. As general blood screening is only undertaken daily before 11 am, it is often the case that patients have to return to have their set of blood tests completed.

Once tests have been taken, a patient must make a further appointment with an infectious disease doctor, usually 1 month in advance, to receive test results. At this point, a patient is referred to multiple further specialists, including dentist, dermatologist, gynaecologist (for women), fluorography and

consultation with a TB-specialist, ultrasound of the abdominal region and a psychologist. Some are located within the AIDS Centre, and some are based in local polyclinics, and separate appointments have to be made for each.

All people seeking ART are assessed by the psychologist. At the first appointment, patients receive a questionnaire, to be completed at home, assessing their HIV and ART awareness. At the second appointment, the psychologist considers patients' adherence potential. At this point, patients may be advised to complete several sessions of the Patients' School, designed to maximize ART literacy and future adherence. This part of the process was often described as arduous:

They [can] give you treatment, but you need to visit a psychologist for a couple of weeks or even a month. They wanted to assess my treatment readiness. Whether I was a 'chosen one'. I completed a million tests: about tolerance to stress, psychological portrait. They had questions like 'If you feel bad, will you stop taking pills?'; 'Do you want to receive treatment?'; 'Do you really want it for yourself or has someone told you had to?'. (Evgeniy, 25 years)

Evgeniy goes on to note that the assessment of adherence potential operated as a way of rationing treatment in relation to patients' assessed 'deservedness', which for people who use drugs appeared explicitly under question:

I thought it was a formality, but it was not. I knew a girl who didn't get the 'magic ticket'... It seems that they say 'Why should we waste our medications on him', as if he is paying for it! That's how they treat you. It's not really up to them to decide to give or not to give medications. They have the power to prescribe pills, and they should prescribe them to people in need. (Evgeniy, 25 years)

Subject to the psychologist's assessment, patients have to make a third appointment with the infectious disease doctor to arrange a treatment regime and prescription. At this point, a doctor can still recommend against treatment if a patients' drug or alcohol use is judged to have adverse effects upon adherence (discussed later). To receive treatment, patients require a passport and residential registration in the Sverdlovsk region.

This labyrinthine process of accessing treatment has the effect of delaying treatment initiation, including for those in urgent need. As Inna, a patient at the TB clinic with a CD4 cell count of 66, explains of the delays introduced by the need to complete psychological assessments:

I've been here [at the TB hospital] for almost 2 months already. I visited the AIDS Center several times, but they kept sending me away: 'Go here, go there. Go to a psychologist'. I did. 'Go again to a psychologist'. Then this psychologist is on holiday. Then my doctor is on holiday. Half a year passes. (Inna, 27 years)

For Inna, there is a potentially tragic collision between her need for crisis treatment and the time it takes for the system to administer her care. While she appreciates the rationale

underpinning psychological assessments of adherence potential, she is acutely aware that she does not have time to wait:

That's how they treat you. You don't get any help... Complete a stupid questionnaire. Loads of questions. And then you have to return to complete other tests. They are preparing you to adhere to the regime. But if I am ready to fight for my life, just give it to me! I have just one more week to live, so they say. (Inna, 27 years)

For Lilyia too, who had yet to initiate treatment, the process of accessing ART had taken 8 months since the time she was told that treatment was urgent on account of her low CD4 count:

It was 46 [CD4] in September. Now it's December. [*Are you on treatment?*] Not yet. They said I had to visit other doctors. Dermatologist, gynaecologist, dentist, psychologist... I don't have time for it, and it's far away, and it's too cold... I wish I could visit them all in one day! But it's not possible. You get an appointment with one doctor, and another is available only in 2 weeks. And then your previous test results have expired, and you have to do it all over again. I had 89 cells back in April. I needed treatment back then. So I'm trying to struggle through all of this since spring! (Lilyia, 25 years)

Lilyia and Inna are persisting, but many do not complete the administrative process. The complexity of the process risks bouncing people from the system, at least until they are next in crisis. Like the story of Oleg above, people may disengage from the treatment system as they find themselves unable to negotiate it. For many PWID, the step towards seeking help from state health services is not a simple one. Health is a relative concern, situated in a context of competing immediate concerns, including those directly connected to the purchase and use of drugs. The AIDS Centre is geographically distant for many in this large city, and requires long bus journeys. A complex administrative process of accessing ART exacerbates an already fragile help-seeking process:

That hospital [AIDS Centre] is a pain in the ass! Before you could just come and visit a doctor, but now you need to make an appointment. And for that you need a referral. But if you're a regular junkie it's difficult to get out, by public transport, to arrange a referral for the next day, so... I'm a regular, and I don't know what's going to happen to me tomorrow; sometimes there's no money, sometimes there's no 'powder'. Our life is ruled by one law—the 'Murphy's Law'. (Vlad, 34 years)

### **System Catch 22<sup>3</sup>**

There are no official regulations restricting PWID from receiving ART in this setting, although it is a formal requirement of doctors to assess whether a patients' drug or alcohol use might adversely affect treatment engagement. But in practice, as the story of Oleg tells, a patient's disclosure of drug use may contribute to treatment initiation delay. We have noted

elsewhere that a treatment access narrative of ‘treat drugs before HIV’ was common among health providers keen to minimize adherence problems, and that this narrative may also be upheld by would-be patients concerned that their untreated drug use might risk interruption from ART (Rhodes and Sarang 2012). Although direct refusals to provide ART to eligible patients were relatively uncommon, we did receive accounts of ART being withheld from patients on account of their drug use. As Evgeniy recalls:

I just remember being told ‘If you want to get [HIV] treatment, you should quit drugs and come back’. I thought she would give me some information, but no. She said ‘Come back when you quit’. So I left. I thought to myself: if this disease [drug dependency] is not treatable, what kind of treatment is she even talking about? ‘Just quit’, she says! I couldn’t quit for many years. How do I suddenly do it now? (Evgeniy, 25 years)

Treatment system gatekeepers giving priority to the treatment of drug use as a condition of ART risks tragic outcomes when people are seeking HIV treatment belatedly, and can entrap them in a ‘vicious cycle’ of untreated drug use and HIV. In a story, which has some parallels with Oleg’s, Vlad describes what happened to his friend:

I once brought in a friend [to the AIDS Centre] after his wife called me and said he was very ill. He was very bad, couldn’t even stand up. So we took him to the hospital. By the next day, he couldn’t even speak...He died the next day. But you see, he was still using, he was truly addicted. In the AIDS Centre, he had been told that he had a bad [CD4] cell count and they gave him 2 months, and asked him to try and quit drugs in those 2 months. And that once he had quit he should come back. But he continued to shoot up for a month while waiting to be admitted to the drug clinic. He was waiting for a bed. When there was a free bed, he went there and the head doctor said he couldn’t be admitted because of his heart apparently would not withstand the withdrawal. That was it, a vicious cycle. (Vlad, 34 years)

More common, were treatment initiation delays brought about by what PWID perceived as ‘special treatment’ prolonging or complicating the initiation process. As Egor explains:

Drug users are treated in a special way. I had one such doctor. She immediately assessed my state and when I asked about my next steps she said I had to bring her a note from a narcologist. What kind of note? Why? I couldn’t get it. She was saying something like ‘Go don’t-know-where, bring don’t-know-what’. After that, I just stopped going there. (Egor, 27 years)

Like Evgeniy above who cast himself as one of the ‘chosen ones’, Egor accentuates the socially contingent nature of access to ART decisions. These are decisions not simply based on clinical factors but which are felt by would-be patients as ‘judgements’ upon their lifestyles, and even character. Egor

describes his appointments as being akin to ‘a court room’ experience:

If the judge is in a good mood you are lucky. It is the same with doctors. If there are in a good mood, they will talk to you. Otherwise they will send you away. (Egor, 27 years)

It is inside the ‘special relationships’ which are forged between PWID and their differentiated negotiation of access to ART—seen most concretely in cases where access to ART becomes contingent upon patients’ demonstrating commitment towards treating their drug use—that we can see the coming together of systemic and structural factors mediating ART access. Aside from its questionable clinical rationale regarding the prolonging of treatment initiation delay (Lundgren *et al.* 2008), a number of participants described the instruction to treat their drug use as a prior condition of HIV treatment as a ‘Catch 22’. Patients may be invited to cleanse themselves of their drug problems yet the factors perceived to prevent this from becoming possible are fundamentally structural (Rhodes and Sarang 2012). This is because the drug treatment available in this setting is almost universally perceived as ineffective, for reasons of cost, efficacy and quality, as well as for breaches of confidentiality and human rights. This description of the lack of effective drug treatment offered by Vanya—an injector fully engaged in his own HIV treatment as well as in the assistance of others’ access to ART—is typical:

There is no [drug] treatment whatsoever. How many of our patients do I know who have been admitted 7 or 8 times to narcology and who have come out the next day, or day after, and have started using again? Help is neither available nor effective. It is very difficult to call it ‘treatment’. It is simply a way of making money for the drug specialists. And they know that only too well themselves. I sincerely pity the drug specialists, because I understand that they are competent people and they probably see how ineffectual their work is. The drug treatment services need to change completely. (Vanya, 38 years)

The reputation of the inefficacy of drug treatment services in this city is fore-grounded by the well-publicized practices of the NGO ‘City Without Drugs’. This initiative promotes coerced treatment of drug users, often against their consent, wherein treatment can include forced labour, physical beating, even starvation. This is how Lev describes such treatment:

Have you ever heard of ‘City without Drugs’? Utter insanity. In the rehabilitation centre, they keep people handcuffed and beat them up. I don’t think you can ever get anything good out of a person with violence and sticks. You can lock them up for a month and whack them regularly, but in a month they’ll get out, stay clean for a while, and then go back to where they were. Even if they know they’ll be brought back, handcuffed and manhandled. It’s not a way to cure them. (Lev, 41 years)

We see then, how the HIV treatment system—by emphasizing directly or indirectly the conditionality of ART access upon treated drug use—acts to ‘institutionalize’ structural deficits in

the delivery of drug and HIV treatment opportunity. In the way that systems reify structural deficits through their processes of administration and gate-keeping, would-be patients become entrapped by structural deficits beyond their control. While the provision of OST is recognized to enhance ART access, adherence and clinical outcome (Roux *et al.* 2009; Weber *et al.* 2009; Uhlmann *et al.* 2010), such internationally recommended treatment is prohibited in Russia. Yet, its potential does not go unacknowledged by PWID:

Things would be much simpler if it [OST] was introduced...The criminal activity of drug users would decrease significantly. They wouldn't have to steal and rob, and the state would only benefit from this. In every aspect! If such a programme was introduced, it would be introduced in partnership with the AIDS Centre, right? Then everything could be integrated. A lot of infected people would be examined and monitored. Generally speaking, I think it's the best way out. It makes things simple for everyone. (Sasha, 28 years)

#### *System verticalization*

The lack of effective drug treatment opportunity is accentuated further by the vertical structure of the treatment system. There was only minimal drug specialist advice available within the AIDS Centre, where all HIV treatment issues were handled. More critically for those co-infected with TB, there was no formal integration or co-location of TB and HIV or drug treatment services. Regional bureaucracy made the provision of city-based drug treatment services within regional TB hospitals impossible. The absence of drug treatment in the TB clinics had the effect of undoing co-infected patients' adherence to their TB treatment, for patients would find ways of 'escaping' the hospital to 'self-treat' their withdrawals. This had the risk of many interrupting their treatment:

There isn't any help...They say they go to the specialist drug clinic...I went and injected myself and then went back to the hospital...I was back by lunchtime, back at the hospital. (Ulyana, 30 years)

With no immediate solution to this structural problem of system verticalization, hospitalized patients have no immediate access to drug treatment, and the tendency is for the system to 'remove' the 'problem' of untreated drug use by discharging such patients from the TB hospital. As was described:

Drug users are discharged in an indeterminable state. A person might break a rule—that's it, he is shown the door. He is HIV positive, has tuberculosis. It is a miracle he is still standing and that is it, he is told to go home and die. (Vanya, 38 years)

Similarly, system verticalization compromised access to ART for patients co-infected and hospitalized with TB. At the time of the study, there was no delivery of ART to the TB hospital. This meant that co-infected patients' access to ART was dependent upon them making an hour long bus journey across the city to attend the AIDS Centre. Quite apart from this being

questionable from the perspective of community TB control, this had the effect of disrupting access to ART for those for whom consistently delivered ART is life saving.

## Discussion

While universal access to HIV treatment and care is promoted internationally as part of evidence- and rights-based approaches to developing HIV policy, this qualitative study among PWID in the Russian city of Ekaterinburg finds that access to ART is socially contingent. There is increasing recognition of the need to unpack how environmental factors mediate the delivery of HIV treatment in lower income and transitional settings (Rhodes *et al.* 2009; Krusi *et al.* 2010; Wolfe *et al.* 2010). Although described as an 'evidence-based hope' given the dramatic successes of global scale-up efforts (Kazatchkine 2008), 'universal access' to ART remains an aspiration in many real world settings. We therefore emphasize that 'universal access' is inevitably a product of its social context. Qualitative research is ideally suited to unpacking the context-based nature of access to ART, though there is relatively little such research, especially among PWID or in concentrated HIV epidemics (Mshana *et al.* 2006; Campero *et al.* 2007; Maher *et al.* 2007; Caltado 2008; Rhodes *et al.* 2009). Without such research, the inequities of ART become overlooked in the rhetoric of global scale-up.

Our findings accentuate the role of systemic barriers in accessing ART in a setting of large HIV treatment need. The HIV treatment and care system in the Sverdlovsk region is one of the most advanced in the Russian Federation, and has made considerable efforts to make its services accessible. But our findings emphasize that treatment systems do not operate as separate entities unattached from their social contexts but instead reproduce those contexts, thus having 'social effects' which can be 'iatrogenic' in their impacts. We identified three core themes across participants' interview accounts: 'labyrinthine bureaucracy' governing access to ART; a 'system Catch 22' created by an expectation that access to ART or TB treatment was conditional upon treated drug use in a setting of limited effective drug treatment opportunity; and 'system verticalization' compromising access to ART and drug treatment, especially for those co-infected with TB.

#### **System practices reproducing structural inequities**

We found that the 'labyrinthine bureaucracy' of the treatment system, especially the appointments and assessment process, served to make the system extremely complex and time consuming to navigate. This fed a tendency towards delayed treatment initiation as well as a failure to complete the treatment initiation process. There was a tendency for people to seek help for their HIV disease when already in crisis, and often when it was too late for the system to have positive effect. Evidence internationally emphasizes the critical clinical importance of early treatment initiation (Lundgren *et al.* 2008). With the administrative practices of the treatment system implicated in the reproduction of treatment initiation delay, as well as patients' disengagement from the treatment system, we can see the potential for helping systems to exacerbate harm.

The process towards seeking help from state services among PWID may be especially fragile given a wider context emphasizing



the criminalization and stigmatization of drug users (Human Rights Watch 2007; Sarang *et al.* 2010). Given the delicacy of this process, where would-be patients' attachment to a helping service may be shrouded in doubt and hanging by a thread, the potential for systemic factors to disrupt pathways to access are great. This is especially the case given the situated relativity of HIV treatment concern among PWID.

We can glimpse how system practices reproduce structural inequities in people's accounts of the psychological assessments they receive as a condition of accessing ART. While developed by the system to enhance treatment adherence, we find that psychological assessments may be experienced by patients as a form of moral discipline based upon doctors' judgements of their 'deservedness', which in practice contribute to treatment initiation delay, as well as sometimes treatment rationing and refusal. Many people we interviewed spoke of how the system enabled 'special treatment' for drug users, whereby their access to ART was felt to be less certain than necessary. Ethnographic studies elsewhere have pointed to the 'disciplinary' effects of ART administration (Biehl 2007; Nguyen *et al.* 2007).

The reproduction of structural inequities through ART administrative practices was most visible in cases of treatment refusal. Nationally, PWID are disproportionately represented in ART. A survey of 20 regions in Russia found that two explicitly stated that PWID do not qualify for ART and/or will only receive such treatment when their condition has worsened to include multiple opportunistic infections (Foundation for Intersectoral Partnership 2009). It is naive to assume that in politically charged and resource-constrained contexts clinical decisions are based on clinical indicators alone (International Treatment Preparedness Coalition 2007). Refusal to provide ART to patients in need violates human rights and medical ethics. More practically, it points to the need to develop clearer standardized protocols for the clinical management of treatment initiation which are lacking in Russia (Foundation for Intersectoral Partnership 2009). The lack of standardized clinical protocols for HIV treatment makes it difficult to hold clinicians accountable for making ART accessible to all in need (Parfitt 2011).

Similarly, we found the treatment system to reproduce structural inequities in its tendency to make access to ART and TB treatment conditional upon the treatment of drug use for which participants felt there to be limited effective treatment options. We described this, as did some of our participants, as a 'Catch 22', where patients' access to ART becomes contingent not only upon their personal capacities to treat their drug use but more fundamentally upon policy-level barriers to effective drug treatment. Evidence internationally emphasizes the pivotal role of OST in enhancing ART access and outcome among PWID (Lucas *et al.* 2006; Roux *et al.* 2009; Weber *et al.* 2009; Uhlmann *et al.* 2010). The policy of prohibiting OST in Russia has iatrogenic effects (Rhodes *et al.* 2010). The 'problem' of untreated drug use for ART access is not simply a matter of individuals' decision-making but points to the urgent need for structural changes to bring about approaches to drug treatment closer in line with those recommended internationally. This 'Catch 22' is an exemplar of the coming together of systemic and structural factors affecting access to ART; a process of 'structuration' (Giddens 1984), whereby (meso) institutions reproduce their (macro) social contexts.

Finally, we found that 'system verticalization', a legacy of the Soviet health system, compromised co-infected patients' access to ART, as well as undermined adherence to TB treatment through lack of linked drug treatment opportunity. With TB a significant cause of death among people living with HIV in Russia, system verticalization exacerbates the potential for iatrogenic effects (Dimitrova *et al.* 2006; Gelmanova *et al.* 2007). Integrated, including co-located, HIV and TB services can be critical in determining health outcome among people living with HIV, including among PWID (Sylla *et al.* 2007; Altice *et al.* 2007; Havlir *et al.* 2008). Evidence also suggests the need to broaden the focus of integrated combination treatments to encompass social support as well as structural interventions, for example linked to housing, transport and legal aid (Wolfe *et al.* 2010; Lambers *et al.* 2012).

## Conclusion

The pledge towards 'universal access' to HIV treatment demands an appreciation of just how relative access to ART can be. We find that various administrative practices of the treatment system act as important mediators of access to ART and that these are not unattached from the local social contexts in which they are produced but rather reproduce those contexts. This accentuates an interplay of meso-level systemic and macro-level structural factors in the 'structuration' of inequities of access to ART. Critical in this setting are structural interventions to simplify bureaucratic and assessment procedures; enhance patient treatment literacy and engagement; foster integrated HIV, TB and drug treatment services; and advocate for policy reforms to drug treatment provision.

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## Conflict of Interest

None declared.

## Endnotes

- <sup>1</sup> The phrase 'Catch-22' emanates from the 1953 novel by Joseph Heller of the same name, and has come to describe a 'no win' or 'double bind' situation, whereby the only solution for a problematic situation is denied by a circumstance inherent to the problem itself. We use this phrase because it is also grounded in the accounts of participants themselves.
- <sup>2</sup> Of the eight people who reported that they had stopped injecting, it is possible that some were in fact currently injecting but reported otherwise. This is not uncommon when attempting to access services and as a means of avoiding becoming officially registered as an active drug user. We found no evidence of difference in the accounts between those currently and previously injecting with respect to how people experienced systemic barriers to ART access, though two cases (Lucya and Vitaly) expressed greater levels of treatment literacy on account of having worked with the AIDS Centre in the past.

## References

- Alice FL, Maru DS, Bruce RD, Springer SA, Friedland GH. 2007. Superiority of directly administered antiretroviral therapy over self-administered therapy among HIV-infected drug users: a prospective, randomized, controlled trial. *Clinical Infectious Disease* **45**: 770–8.
- Bernays S, Rhodes T, Janković Teržić K. 2010. 'You should be grateful to have medicines': continued dependence, altering stigma and the HIV treatment experience in Serbia. *AIDS Care* **22**: 14–20.
- Biehl J. 2007. *Will to Live: AIDS Therapies and the Politics of Survival*. Oxford: Princeton University Press.
- Bobrova N, Sarang A, Stuijke R, Lezhentsev K. 2007. Obstacles in provision of anti-retroviral treatment to drug users in Central and Eastern Europe and Central Asia. *International Journal of Drug Policy* **18**: 313–8.
- Bobrova N, Rhodes T, Power R *et al.* 2006. Barriers to accessing drug treatment in Russia: a qualitative study among injecting drug users in two cities. *Drug and Alcohol Dependence* **82**(Suppl 1):S57–63.
- Caltaldo F. 2008. New forms of citizenship and socio-political inclusion: accessing antiretroviral therapy in a Rio de Janeiro favela. *Sociology of Health and Illness* **30**: 900–12.
- Campero L, Herrera C, Kendall T, Caballero M. 2007. Bridging the gap between antiretroviral access and adherence in Mexico. *Qualitative Health Research* **17**: 599–611.
- Dimitrova B, Balabanova D, Atun RA, Levicheva V, Coker RJ. 2006. Health service providers' perceptions of barriers to tuberculosis care in Russia. *Health Policy and Planning* **2**: 265–74.
- Donoghoe MC, Bollerup AR, Lazarus JV, Nielsen S, Matic S. 2007. Access to highly active antiretroviral therapy (HAART) for injecting drug users in the WHO European region. *International Journal of Drug Policy* **18**: 271–80.
- Elovich R, Drucker E. 2008. On drug treatment and social control: Russian narcology's great leap backwards. *Harm Reduction Journal* **5**: 23.
- Foundation for Intersectoral Partnership. 2009. *Ways to Optimize and Improve the Quality of Medical Services for People with HIV in the AIDS Centres of the Russian Federation*. Moscow: FIP (in Russian). <http://www.hivpolicy.ru/publications/index.php?publisher=209&order=date&id=697&file=1477>. January 3, 2012.
- Gelmanova IY, Keshavjee S, Golubchikova VT *et al.* 2007. Barriers to successful tuberculosis treatment in Tomsk, Russian Federation: non-adherence, default and the acquisition of multidrug resistance. *Bulletin of the World Health Organization* **85**: 703–11.
- Giddens A. 1984. *The Constitution of Society*. Cambridge: Polity.
- Havlin DV, Getahun H, Sanne I, Nunn P. 2008. Opportunities and challenges for HIV care in overlapping HIV and TB epidemics. *Journal of the American Medical Association* **300**: 423–30.
- Human Rights Watch. 2007. *Rehabilitation Required: Russia's Human Rights Obligation to Provide Evidence-Based Drug Dependence Treatment*. New York: Human Rights Watch.
- International Treatment Preparedness Coalition. 2007. *Improving AIDS Drug Access and Advancing Health Care for All*. Missing the Target Bulletin 5. <http://www.aidstreatmentaccess.org/itpc5.pdf>. January 3, 2012.
- Kazatchkine M. 2008. *Access to Prevention and Treatment of AIDS in the Developing World: Evidence for Hope*. Department for International Development Lecture Series, London School of Economics.
- Krusi A, Wood E, Montaner J, Kerr T. 2010. Social and structural determinants of HAART access and adherence among injection drug users. *International Journal of Drug Policy* **21**: 4–9.
- Lambers FAE, Stolke IG, van den Berg CHSB, Coutinho RA. 2012. Harm reduction intensity: Its role in HAART adherence amongst drug users in Amsterdam. *International Journal of Drug Policy* **22**: 210–8.
- Lucas GM, Mullen BA, Weidle PJ *et al.* 2006. Directly administered antiretroviral therapy in methadone clinics is associated with improved HIV outcomes, compared with outcomes among concurrent comparison groups. *Clinical Infectious Disease* **42**: 1628–35.
- Lundgren JD, Babiker A, El-Sadr W *et al.* 2008. Inferior clinical outcome of the CD4+ cell count-guided antiretroviral treatment interruption strategy in the SMART study. *Journal of Infectious Diseases* **197**: 1145–55.
- Maher L, Coupland H, Musson R. 2007. Scaling up HIV treatment, care and support for injecting drug users in Vietnam. *International Journal of Drug Policy* **18**: 296–305.
- Melgaard B, Creese A, Aylward B *et al.* 1998. Disease eradication and health systems development. *Bulletin of the World Health Organization* **76**: 26–31.
- Mshana GH, Wamoyi J, Buasza J *et al.* 2006. Barriers to accessing antiretroviral therapy in Kisesa, Tanzania: a qualitative study of early rural referrals to the national program. *AIDS Patient Care and STDs* **20**: 649–57.
- Nguyen VK, Ako CY, Niamba P, Sylla A, Tiendrebeogo I. 2007. Adherence as therapeutic citizenship: impact of the history of access to antiretroviral drugs on adherence to treatment. *AIDS (Suppl 5)*:S31–5.
- Parfitt T. 2011. Russia's drug supply system leaves HIV patients wanting. *Lancet* **377**: 369–70.
- Rhodes T, Bernays S, Janković Teržić K. 2009. Medical promise and the recalibration of expectation: hope and HIV treatment engagement in a transitional setting. *Social Science and Medicine* **68**: 1050–9.
- Rhodes T, Sarang A. 2012. Drug treatment and the conditionality of HIV treatment opportunity: a qualitative study in a Russian city. *Addiction* **107**: 1827–36.
- Rhodes T, Sarang A, Vickerman P, Hickman M. 2010. Policy resistance to harm reduction for drug users and the potential effect of change. *British Medical Journal* **341**: c3439.
- Roux P, Carrieri MP, Cohen J *et al.* 2009. Retention in opioid substitution treatment: a major predictor of long-term virological success for HIV-infected injection drug users receiving antiretroviral treatment. *Clinical Infectious Disease* **49**: 1433–40.

- Sarang A, Rhodes T, Shoen N, Page K. 2010. Policing drug users in Russia: risk, fear and structural violence. *Substance Use and Misuse* **45**: 813–64.
- Sylla L, Bruce RD, Kamarulzaman A, Altice FL. 2007. Integration and co-location of HIV/AIDS, tuberculosis and drug treatment services. *International Journal of Drug Policy* **18**: 306–12.
- Taktchenko-Schmidt E, Atun R, Wall M *et al.* 2010. Why do health systems matter? Exploring links between health systems and HIV response. *Health Policy and Planning* **25**: 283–91.
- Uhlmann S, Milloy MJ, Kerr T *et al.* 2010. Methadone maintenance therapy promotes initiation of antiretroviral therapy among injection drug users. *Addiction* **105**: 907–13.
- United Nations General Assembly Sixtieth Special Session. 2006. *Political Declaration on HIV/AIDS*. Resolution 60/262 adopted by the United Nations General Assembly, New York: United Nations.
- Weber R, Huber M, Rickenbach M *et al.* 2009. Uptake of and virological response to antiretroviral therapy among HIV-infected former and current injecting drug users and persons in an opiate substitution programme: the Swiss HIV cohort study. *HIV Medicine* **10**: 407–16.
- Wolfe D. 2007. Paradoxes in antiretroviral treatment for injecting drug users: access, adherence and structural barriers in Asia and the former Soviet Union. *International Journal of Drug Policy* **18**: 246–54.
- Wolfe D, Carrieri MP, Shepard D. 2010. Treatment and care for injecting drug users with HIV infection: a review of barriers and ways forward. *Lancet* **376**: 355–66.
- Wood E, Hogg RS, Kerr T *et al.* 2005. Impact of accessing methadone on the time to initiating HIV treatment among antiretroviral-naïve HIV-infected injection drug users. *AIDS* **19**: 837–39.