Russia’s drug-supply system leaves HIV patients wanting

Tom Parfitt
Russia’s federal law guarantees antiretroviral drugs to all those who need it. So why are HIV patients across the country unable to get hold of treatment? Tom Parfitt reports from Moscow.

The explanation was short. “My doctor just said there were no more tablets, they hadn’t received them”, remembers Svetlana.

In August, 2010, the 27-year-old from Tula, an industrial city in western Russia, had gone to receive her monthly dose of antiretroviral (ARV) drugs from the regional AIDS centre. “They changed my treatment scheme and for 3 months I had to take a different course of drugs”, says Svetlana, who was diagnosed with HIV 10 years ago.

Now she worries that the virus might have built up resistance to the drugs she was prescribed before the change. “I’m upset, of course”, she says. “I want to live.”

Svetlana’s situation is far from unique. In 2010, the Russian branch of the International Treatment Preparedness Coalition undertook a monitoring project called Simona+ to assess the scale of shortages of ARV drugs in 20 cities.

Between January and November, the group questioned 1146 people and noted delays in patients' treatment in 11 cities: Zlatoust, Orsk, Moscow, Kaliningrad, Naberezhnye Chelny, Orenburg, Saint Petersburg, Irkutsk, Kazan, Biysk, and Krasnoyarsk.

ARV drugs usually involve taking a combination of three or four drugs that are chosen to inhibit HIV according to the stage of the life-cycle of the virus in each patient.

Yevgeniya Maron, coordinator of the Simona+ project, says interruptions and changes in treatment can have extremely serious effects. “It’s very important what's replaced with what”, she says. “You need to look at the individual case of each patient. If you’re talking about long-term treatment the changes can be harmful. A resistance can build up to a particular drug, or to a whole class of them. And there are side effects like skin irritations, nausea, and headaches.”

Eastern Europe and central Asia have the fastest growth rate of HIV in the world and Russia accounts for between 60% and 70% of the epidemic. Whereas India and some African countries have the largest populations of people living with HIV, the amount of new infections in these places every year has stabilised or dropped. By contrast, the epidemic in Russia peaked in 2001, dipped, and has risen steadily since 2004. In 2009, there were 58 448 new cases of infection, up 8% on 2008. Early data for 2010 show no halt in the increase.

About 70 000 people in the country are officially receiving ARV treatment—administered through a network of regional AIDS centres—although some officials and non-governmental organisations estimate that 50 000 more require treatment.

There are no precise data for how many people have been affected by glitches in supply. Russia’s ministry of health and social development, which is responsible for the system of drug provision, has downplayed the problem. “Talk of there not being enough [ARV] medicines for thousands of people are groundless”, said Marina Shevyreva, director of the ministry’s health protection department, in September last year, adding that “in the majority of regions there is no problem with the provision of medicines”.

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However, that position was undermined at the end of 2010 when the general prosecutor's office announced it had ordered the ministry to rectify “numerous violations” in the purchase and distribution of ARV drugs.

Prosecutors said that “inadmissibly” the ministry had advertised tenders for procurement late and not agreed contracts for drugs with suppliers for 2010 until the autumn of that year. As a result, Ulyanovsk region received only 35% of the necessary stavudine, while Chelyabinsk got 6.8% of its didanosine, and Omsk received only 2.4% of its didanosine, and 1.7% of the required zidovudine.

Anecdotal evidence, surveys, and a series of court cases also corroborate reports of a system beset by problems.

Activists say shortages have been so acute that an informal market has developed to allow patients to swap drugs to keep their treatment programmes on track. “Our newsletters are full of people from different regions trying to exchange supplies”, says Pavel Aksenov of Esvero, a network of organisations that aims to cut HIV-risk behaviour among injecting drug users. “If you stop taking antiretrovirals for just a few days then resistance can build up and they become redundant. We are talking about lives at risk.”

A website called pereboi.ru—from the Russian word for “stock-outs”—is one place where the exchanges take place. While some visitors describe their predicament in detail, others leave terse messages about the drugs they are seeking. “I really need Stavudine”, writes Inga from Volgograd, in a typical message posted on Dec 17, 2010. “The AIDS centre says there isn't any. Whoever has some, please share.”

Marina, a 28-year-old student in Moscow who asked not to give her surname, tells The Lancet she had been forced to seek assistance via the internet when her doctors said in April, 2010, that one of her three drugs was no longer available. “I found help on the forums for people living with HIV because I didn't want to take an alternative drug that my doctor offered”, she says. “Someone brought me supplies from St Petersburg and I used them for 3 months.”

Marina said other patients at the Moscow AIDS centre had waited over half a year before supplies were restarted. “Every month I go to the centre, sit in the queue and hear negative comments about how people have had one medication changed for another, and things have gone badly with the new drug”, she adds.

The situation has led some activists to take to the streets. On World AIDS Day on Dec 1, 2010, about 20 people held a mock funeral outside the White House, the Russian Government building in Moscow. Dressed as nurses and bears, the activists held a wreath saying “Treatment: Rest in Peace”. Alexandra Volgina, one of the HIV-positive people who took part, told reporters: “Today, we buried our last hopes to be heard. The state leaves us no choice—we will die without the necessary medications.”

The campaign has even gone international. In October, 19 people living with HIV in Russia sent a complaint to Anand Grover who was appointed as the UN Special Rapporteur on the Right to Health in 2008.

The authors of the letter—who requested anonymity—described personal experiences in which doctors had: interrupted ARV treatment for prison inmates for up to 1 month; changed treatment regimes for patients due to non-medical reasons; denied treatment altogether to some HIV
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sufferers; and provided one-drug and two-drug treatments rather than the three-drug therapy recommended by WHO.

Grover's office has yet to confirm whether it will seek a response from Russia to the complaint. The cries for help have not gone entirely unheeded in Russia. Activists have an ally in Vadim Pokrovksy, the influential head of the federal AIDS centre, based in Moscow, who has voiced his support for legal challenges in the courts against centres failing to provide ARV drugs.

Nine HIV-positive people in Moscow, Kazan, Tula, and Arkhangelsk managed to obtain their regular drugs after they sued AIDS centres with the help of a human-rights watchdog called Agora.

Anya Sarang, president of the Andrey Rylkov Foundation, an advocacy group for people with HIV that is named after an outreach worker who died in 2006, says the system of ordering and estimating quantities of ARV drugs is fundamentally flawed.

“There is no national register of patients receiving treatment and there are no protocols giving clinical guidance on what immune status and viral load in patients should oblige doctors to start providing ARV medications”, she says. “The local AIDS centres report their calculations of the number of patients requiring treatment every year but they often underestimate these figures because without proper criteria it's a kind of guesswork.”

In turn, officials who control the procurement process in Moscow pressure the AIDS centres to cut their estimates because the budget is limited.

Pricing of drugs bought with money for antiretroviral drugs provided to Russia by the Global Fund to Fight AIDS, Tuberculosis and Malaria is tightly controlled, but federal procurement is slack. Members of parliament from the state duma, the lower house of parliament, complained to the ministry of health in November, 2010, that it is paying suppliers five to eight times the going rate for ARV drugs, suggesting corruption in the process. The ministry has yet to respond to the complaint.

Sarang says a greater problem is that tens of thousands of people requiring ARV treatment are “totally outside the system” because they cannot overcome the hurdles to accessing care.

Injecting drug users (IDUs) are especially vulnerable, she says. “They are told, “You'll have to kick your drug habit before we can treat you for HIV.” But in Russia this is like saying, “Go away and die' because there is no replacement therapy for opioid dependence and very little outreach support for IDUs.”

Care is not allocated according to clinical factors alone, but only after each person with HIV has gone through a series of commissions that examine his or her “social responsibility” and psychological state. “We need a new vision for providing ARV treatment but so far I'm not optimistic because the ministry of health is in denial about the scale of the problem”, says Sarang.