

Russia's blossoming civil society holds the key to HIV

Russia's leaders are facing an HIV epidemic that experts believe could become a national disaster. But ignorance and ingrained prejudices among the general population hinder efforts at control. Is Russia's nascent civil society strong enough to meet the challenge? Hannah Brown reports.

"I'm going to give up on Monday", promises Vadim with a wry smile, before listing heroin, cannabis, and hunka—a home-made opiate common in the west Siberian city of Tomsk, where Vadim lives—among the drugs he has been hooked on since 1993. "But it's not so easy to stop. Even if you don't feel a physical dependence."

As a young male drug user, Vadim, 29, could be the epitome of Russia's HIV epidemic. But he is not infected—at least not yet. After contracting hepatitis from sharing needles a few years ago, he has been a meticulous visitor to Tomsk's needle-exchange centre, housed in an anonymous dust-caked building on the city's outskirts. "There's no place to get clean needles other than here", he says.

The centre keeps tabs on its visitors, and operates under the watchful, if distant, eye of the authorities, but Vadim is worried enough about contracting HIV make sure his regular visits include blood tests. "My wife doesn't use drugs, so I have to be tested regularly to protect her", he explains.

Vadim blames his addiction on the turmoil that followed the Soviet collapse at the beginning of the 1990s, when the social institutions that had kept children like him on the straight and narrow imploded. "Teachers didn't want to teach", he explains. "There was no information about drugs, and it was fashionable." So, with time on his hands, and cheap drugs in plentiful supply, Vadim, like millions of his compatriots, succumbed to the lure of illegal intoxication.

This post-Soviet drug-use explosion paved the way for an HIV epidemic labelled by the Global Fund to Fight AIDS, Tuberculosis, and Malaria as the fastest spreading in the world.



Youth at risk: 80% of Russia's officially registered HIV cases are young people 15–30 years old

Although the virus was initially introduced to Russia through sexual transmission, it was the thousands of drug users sharing needles that propelled it forward. By the end of 1995, there had only been seven cases out of a total of 1062 in which transmission was attributed to drug use. But over the next 10 years, unsafe injecting accounted for a massive 76% of the 342 000 official cases. UNAIDS believes the actual numbers could be twice as high.

Crisis point

For international onlookers, Russia's HIV epidemic is now at a crucial stage. Rates of new infections seem to be levelling off, but scientists fear this development is not, as it might seem, a sign that control efforts are starting to work. Rather, the slowdown may indicate that the virus is leaving the confines of high-risk groups—drug users, commercial sex workers, and men who have sex with men—and is slowly seeping into the general population. The drop in new cases can be explained by the difference

in efficiency of transmission routes: for drug users sharing needles, the chance of passing on HIV is close to 100%; for heterosexual partners, one of whom is infected, the probability of transmission can be as low as 1%.

Until this year, however, President Putin had seemed largely oblivious to the concerns of scientists and international AIDS organisations about Russia's burgeoning HIV crisis. A federal anti-AIDS law guaranteeing free medical care and social support for HIV-positive people was passed without any spending recommendations or action points. Prevention and treatment efforts were persistently starved of funds. And the lack of federal support for the country's hundred or so AIDS centres—part of a Soviet-designed nationwide network isolated from the rest of the health-care system—left them with no option other than to look to international health agencies and western non-governmental organisations (NGOs) for help.

Fortunately, aid has come, most notably from the Global Fund, now

the country's largest external HIV/AIDS donor. The knock-on effects of this commitment seem also to have pushed HIV up the domestic agenda, evinced by this year's 20-fold federal funding increase, last month's pledge to fully reimburse the Global Fund for its grants, and Putin's powerful rhetoric on HIV/AIDS during Russia's first stint in the G8 chair.

But there has been a high price paid for the president's procrastination on HIV, in the form of continuing ignorance about the virus among the general population. Sociological studies suggest that risky behaviours are getting more, not less, common in Russia, because people do not understand enough about AIDS. It is this situation that Russia's nascent civil society is now working hard to change.

Uncivil society

As more of a managed democracy than a free one, the formation of activist groups to articulate the priorities of the populous and fight for individual rights in Russia has been slow and sporadic. But one beneficial side-effect of the country's reliance on external aid to combat HIV is that the international attention has helped strengthen the country's civic institutions—an essential component of successful anti-HIV efforts in all parts of the world.

These reenergised organisations do, however, have their work cut out. According to Alexey Bobrik, head of the GLOBUS project, a consortium of national and international NGOs which runs HIV prevention and treatment projects in 10 Russian regions, the general attitude towards HIV in Russia "is still one of denial and widespread stigmatisation, even in health facilities".

He says dental care and operations are routinely denied to HIV-positive people because of their infection status. And, he adds, the government requirement that infected individuals receive medical care only at AIDS centres essentially amounts to a public branding of HIV-positive people that perpetuates their marginalisation.

Richard Feachem, Executive Director of the Global Fund, has said of Russia's misconceptions about HIV that "denial of that degree puts Russia behind China and India, both of which have overcome the issue".

Part of the problem is that next to the heavy tolls wrought by Russia's daunting population-wide health burdens, which include very high rates of heart disease, alcoholism, and tuberculosis, the number of HIV cases is tiny. It simply isn't a serious health problem yet, Bobrik explains. "Many people in Russia don't believe it is a big social problem because of the low

number of deaths and the fact that they are confined to groups such as drug addicts and other marginalised populations", he says. These beliefs are not only a problem for educating people at risk, however. They also prevent people already infected from seeking help.

In the southern city of Saratov, on the banks of the Volga river, the clean modern lines of the only AIDS clinic stand in stark contrast to the shabby wooden houses slumped along the neighbouring mud-track streets. Elena, a nurse at the centre, took up her job in 1999 after finding out she was HIV-positive. She now runs a peer-support group for people who come to the clinic for testing or treatment. "They all say it is so nice just to be normal people. We are always reminded about our disease, so it is a relief to have the opportunity to meet and discuss not as patients but as people", she says.

Luba Potemina, Elena's boss and head physician of the Saratov centre, says one of their main tasks is to "make sure that HIV-positive people don't feel any different from people with diabetes or vascular disease". Infected individuals are not separated from non-infected patients in hospital or maternity wards, which helps decrease discrimination outside the centre's walls, she says.

But the real battleground is in the community, among people too fearful of stigmatisation to seek the necessary treatment. Vitaly, a nervy young man who got engaged to Elena after they met at the AIDS centre, says many people "are afraid that their confidentiality will be breached, or that someone will see them", so they do not attend support meetings.

His experiences of being discriminated against in health centres and at school—he was only allowed to finish studying for the last 2 years on condition that he stayed at home—convinced him that people with HIV need somewhere to meet that is less public than the AIDS centre to get support. He is appreciative of the



Steve Turner

Tomsk's needle-exchange centre hands out sterilisation pads and clean syringes to drug users

work of the AIDS centre, but believes the focus of local NGOs on raising awareness among young uninfected people means people actually living with the virus are ignored, which therefore perpetuates their marginalisation.

Vitaly has now set up his own NGO to help address what he perceives as a significant care gap. "When I was diagnosed, I was just told and that was it. But when people come to us, they feel like someone cares—and that's what's important", he says.

Prevention works

The task of eliminating ingrained prejudices taken on by Russia's new clutch of NGOs is a daunting one, but a pleasant surprise has emerged from the country's recent experiences. What these dedicated groups have shown is how effective small well-run programmes can be, if given sufficient funds and a bit of attention.

Bobrik's GLOBUS project, named for the abbreviation of the Russian translation of Global Efforts Against HIV/AIDS in Russia—and of which Vadim's local needle-exchange centre in the Siberian city of Tomsk is part—is one of the most successful, despite only getting off the ground at the beginning of last year.

In just over 12 months, the GLOBUS project's activities, funded by the Global Fund, have already helped push down antiretroviral drug prices; improve access to prevention and treatment services; and have helped change national AIDS policy, through the lobbying efforts of the organisations it supports. In fact, according to Urban Weber, the Global Fund's Eastern Europe and Central Asia team leader, the region of Eastern Europe and Central Asia, of which Russia is part, "has produced some of the best results of any grants awarded by the Global Fund".

Bobrik attributes much of his consortium's success to the professionalism of NGOs in turning their hands to activities they had little

previous experience of, including large-scale procurement, delivery of equipment, and the organisation of a large number of HIV/AIDS treatment programmes. But Weber believes the reason for the region's spectacular success is simpler. Russia combines four key ingredients: infrastructure, NGOs, government support, and cash. "That's the magic formula", he says.

But just as stigma and discrimination mark the lives of infected individuals, Bobrik says his organisation has encountered numerous problems caused by social resistance to expanding the scope of HIV-prevention activities, particularly those focused on drug use and raising awareness among homosexual men.

In April this year, one GLOBUS site was the subject of a series of attacks sanctioned by the Russian Orthodox Church, during which NGOs were accused of "destroying the moral grounds of society" and even of perpetuating paedophilia. However, Bobrik says such extreme outbursts are not his prime concern since the incident merely served to strengthen and unify the message from "all reasonable peoples—including the government and the academy of medical sciences". A bigger fear, he says, is the law.

After 2 years of subtle indications that drug-use laws were changing to make it easier to prosecute dealers, while protecting users by helping them to kick their habits, the State Drug Control Committee last year decided to re-tighten controls. Bobrik believes this decision will have a negative effect on HIV-prevention efforts by forcing addicts to boycott HIV-information centres because of fear of arrest.

But his greatest worry at the moment is that this move signals a more wide-ranging crackdown—a new Russian "war on drugs"—which could see the end of the legal protection currently extended to harm-reduction sites, such as needle-exchange centres, and put paid to hopes of a reversal in the government's currently strict



Raising awareness about the importance of condom use is a high priority for NGOs

prohibition of substitution treatment, used to help wean drug users off their habit. Without freedom to use substitution therapy when appropriate, international authorities agree that other harm-reduction strategies are next to useless.

Patchy progress

For all their promise, these first forays into civil-society-led HIV prevention in Russia are necessarily small-scale, which means the good results they generate are inevitably isolated, and many regions still have no access to services at all.

For example, a specific criticism of the GLOBUS project in the west-Siberian oblast of Tomsk is that it has focused solely on the urban capital, which excludes many of the region's residents who are at the highest

risk. In the frosty northern oil town of Strezhevoy, which borders the neighbouring high-HIV region of Tyumen, HIV transmission is much higher than in the student-dense capital because of the migration of HIV-positive individuals across the oblast border, and the concentration of heroin dealers bringing drugs into the town to help oil-revenue-rich workers offload their extra cash.

HIV-positive people who have moved to get work are particularly vulnerable because oil companies inevitably prefer to hire new staff members rather than taking care of current ones. And with the recent politically messy break-up of oil-giant Yukos, widespread unemployment has added to Siberia's woes.

System failure

What Russia needs now to help its small-scale successes become sustainable improvements is for its reborn civil-society movement to make a lot more fuss about one issue common to all regions across Russia's great expanse: the fundamental barrier to uniformly good HIV-prevention and control posed by the decaying, fragmented health system.

Since the tight reins of central Soviet control have been loosened, Russia's 89 oblasts have been more or less allowed to go their separate ways when it comes to health. This means there is little uniformity between regions, and huge variations in quality and extent of care. Underfunding, however, is an affliction most regions can claim, and lack of money has led to appalling perversions of the concept of free emergency medical care—even for the HIV treatment promised by law. "In the early and mid-1990s it became routine for hospitals to require patients to provide their own food, linens, bandages, and even essential medications", recalls Bobrik.

What's more, even within regions different segments of the health system have little interaction. Care for people with HIV is the sole responsibility of a



Russia's segregated system of AIDS centres means all HIV tests, even for children, are done by specialists

network of AIDS centres created under the Soviet system at the end of the 1980s and kept separate from the rest of the health system.

This vertical strategy worked fairly well at the epidemic's early stages, when case numbers were small and confined to high-risk groups. Over time, however, the restrictive structure has led to a gulf of misunderstanding about HIV/AIDS between the specialists in AIDS centres and doctors who work in the general health system. Even now, doctors and nurses in non-specialist health facilities are shockingly ignorant of basic facts about the disease.

Now that the epidemic is on a much larger scale, the inflexibility of the system is causing serious troubles. New treatment targets mean thousands of patients have to be treated very quickly all over the country. But the health systems' bias towards expensive tertiary centres and specialist care means there are neither the funds nor the capacity to cope.

Valery Chernyavskiy, a Russian doctor who now works for the Global Fund, believes the roots of these problems lie with the high degree of specialisation in medicine and the corresponding neglect Russia has shown to the discipline of primary care. But, he warns, resolving this misalignment will not come easily because of the vested

interests that specialists have in their work. "The Russian system continues to miss the point", he says. "It has to look to the rest of the world."

The most obvious result of this sad state of affairs is the continued segregation of HIV-positive people through their necessary life-long ties to stigmatising AIDS centres. But the scarcity of local health providers with the capability to support HIV prevention and treatment presents practical problems, too, by hindering proper surveillance and detection of cases. "We need the health system to accurately identify people who are infected, to offer counselling and so on", explains Bobrik. At the moment, it doesn't do so.

Chernyavskiy believes these problems can all be traced back to deficiencies in local democracy—which, like civil society in Russia, is uncommonly weak. "Primary care is not only about GPs in surgeries, but it includes nurses and community involvement at a local level too", he explains.

So, if Russia's newly strengthened social mobilisation movement can turn its attention to health care in general, then system-transforming change should, at last, become a feasible goal to achieve.

Hannah Brown