# WAR, SOVEREIGNTY AND SOCIAL CHANGE IN UKRAINE

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## Responsibility, Trust, and Transformation in Ukrainian Public Health

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### Introduction<sup>1</sup>

Ukraine has one of the most severe HIV epidemics in Eastern Europe, particularly among people who inject drugs (PWID) and their sex partners (Booth et al. 2009; Ukraine 2010). At 0.62 percent, HIV prevalence in the general adult population is twice as high in Ukraine as in the rest of Europe. As of January 2014, there were 139,573 people living with HIV and AIDS officially registered in the country, but the actual number is probably as high as 238,000. It is estimated that 17,000 deaths each year are AIDS-related (World Health Organization 2014). While injection drug use accounts for 36 percent of new HIV cases, heterosexual sex has

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been the predominant route of HIV infections since 2008 (UNAIDS 2010). In some regions of Ukraine, specifically in the south and east, HIV rates among PWID have been estimated as high as 55 percent (Booth et al. 2013; UNAIDS 2010). Advocates within non-governmental organizations (NGOs), as well as Ukrainian and international public health researchers, have been highly critical of the government's response to drug users and others at risk for HIV, as well as people living with HIV and AIDS. The government only established an AIDS center within the Ministry of Health in 2009, after several early failed attempts to institutionalize and sustain a national, coordinated strategy to combat HIV (Ukraine 2010).

The problems with Ukraine's response to HIV are numerous. Access to opioid substitution therapy (OST), a proven method of reducing HIV risk through reduction in injection risk behaviors (Lawrinson et al. 2008), is severely limited in Ukraine. Fewer than 2 percent of people who use drugs in Ukraine currently receive it - due to strict laws regulating its distribution, insufficient funding, and police harassment of both OST clients and clinic staff (Bojko, Dvoriak, and Altice 2013; Golovankvskaya, Vlasenko, and Saucier 2012). (Conditions are even worse in Russia, where OST is illegal.) The system of narcology, a legacy of the Soviet Union, presents a paternalistic and bureaucratic approach to drug use and HIV that includes opiate addict registries, an emphasis on detoxification, and moral judgment of drug addicts (Elovich and Drucker 2008; Golovankvskaya, Vlasenko, and Saucier 2012). In addition, Ukraine lacks routine HIV testing, apart from that offered to - indeed, required of - pregnant women. People living with HIV and AIDS in Ukraine face similar obstacles to treatment and care, including HIV-associated stigma, harassment and discrimination by police and law enforcement, and expensive and unstable supplies of antiretroviral therapy (Mimiaga et al. 2010). The Ukrainian public health response to HIV is further hindered by a dependence on foreign donor organizations such as the Global Fund to Fight AIDS, Tuberculosis and Malaria; the President's Emergency Plan for AIDS Relief (PEPFAR); and the United Nations Development Programme.

As in other countries with HIV crises, NGOs have stepped in to fill the gaps left by the Ukrainian government's response to HIV. These organizations engage in information dissemination campaigns, one-on-one direct outreach through mobile clinics, needle and syringe exchange programs, HIV testing, and various social support programs (e.g., structured referral services, vocational and social support, and drop-in centers) (Global Fund 2006). NGO staff and clients have also engaged in advocacy, for example to change the addiction treatment environment, create more favorable laws and regulations around OST, and reduce the price of antiretroviral drugs (Golovankvskaya, Vlasenko, and Saucier 2012; Harmer et al. 2013). Despite these successes, tensions persist between NGOs, international funding organizations, and the Ukrainian government around issues related to HIV and drug use. These tensions reflect changes in the governance of public health. As Pfeiffer and Nichter (2008) argue, the influx of global aid into resource-poor countries often occurs alongside underinvestment in public services and the proliferation of NGOs. In some, if not most, settings this global aid lands in contexts undergoing economic restructuring in which formerly public goods such as health care are privatized (Pfeiffer 2013). In Ukraine, health care remains public and nominally free, but the health sector is chronically underfunded and woefully underdeveloped (DeBell and Carter 2005; Luck et al. 2014). Moreover, donor aid often promotes narrow interventions and specific projects, rather than development of government health infrastructure and institution-building (Pfeiffer and Nichter 2008). Finally, international donor organizations such as the Global Fund have been criticized as "top-down" and weakly aligned with sub-grantees' priorities (Harmer et al. 2013).

Reliance on international donors also raises questions regarding coordination and oversight (Buse and Walt 1997). Oversight is particularly relevant for Ukraine, given that two large NGOs (the International HIV/AIDS Alliance in Ukraine and the All-Ukrainian Network of PLWHA) – rather than the Ukrainian government – are the country's Prin-

cipal Recipients of Ukraine's Global Fund grant, due to perceived corruption and mismanagement of earlier grants given to the government (Doyle and Patel 2008; Harmer et al. 2013). In addition, NGOs receiving resources can foster resentment from government workers with low salaries (Spicer et al. 2011). Political instability, conflicting ideas about how to address controversial problems such as drug use and HIV, mistrust, and lack of effective mechanisms to influence government policy also heighten the tension between NGOs and governments (Smith-Nonini 2000; Spicer et al. 2011). In this paper, we explore the implications of these tensions on NGO service providers' ideas about who is and should be responsible for HIV prevention and treatment, and the ways in which NGOs strategize to reform or align with the state. We draw on 24 interviews with directors and staff and field notes from site visits to four NGOs that work on issues related to HIV prevention and treatment among people who use drugs. These organizations are located in cities in Ukraine's eastern and central regions, which also experience the highest rates of HIV and drug use: Poltava, Odesa, Sloviansk, and Mikolaiv (Russian: Nikolaev). These interviews and field notes are part of a larger project that collaborates with HIV-related NGOs in Ukraine to develop new HIV prevention programs for drug users and other at-risk populations.

### Forging partnerships/the (in)visible state

It is important to keep in mind that the 'state' is not one monolithic entity, but manifests itself in many different forms and levels. Although public-sector workers such as police and doctors are restrained by rules, regulations, and policies from national, regional, and local governing bodies, they may also exercise autonomy if their views contrast with formal policies (Lipsky 1980). HIV prevention organizations utilize opportunities at various levels and within public service systems to advance their programs and advocate for clients. While many HIV-related service providers in the NGO sector think that strong partnerships between NGOs and the state would ideally be the most effective strategy for combatting HIV and drug use, they generally

have little hope for state-level reform.

Several models - both idealized and realized - of working with the state emerged from our interviews with HIV prevention service providers. Each invoked different perceptions of the extent to which the state could be reformed, and contrasting views about who should ultimately be responsible for HIV prevention, particularly among marginalized populations. A few agencies have attempted to influence change at higher levels, including legislative and political reform. For instance, a large HIV service organization in Odesa has used coalition-building with other health-related NGOs to spearhead efforts to reform legislation related to drug use and lobby for a National Strategy on Harm Reduction as the state undertakes health-care reform. More common than attempts to reform the state are agency initiatives to cooperate with various state institutions in myriad ways. For example, many HIV prevention organizations staff their mobile HIV testing clinics with doctors who are employees of state-run, regional AIDS centers.

On the one hand, agencies such as the one mentioned above envision a system of social contracting, where, ideally, the state would take over responsibilities of HIV prevention with a comprehensive national strategy, and then engage NGOs in social contracting. On the other hand, the agency in Poltava advances a model of state reform 'from the bottom up', with the state eventually taking full responsibility for HIV prevention. Both models require the state to fully commit to HIV prevention and the populations most at risk for contracting the disease. The models are based on the belief that the state can be reformed, even at a very slow pace. As the director of the agency in Poltava told us:

It is clear that, at least in the next five years, no colossal changes are going to happen [at the national level]. And even if they do, it will be two to three years before the changes trickle down to the cities [like Poltava]. You can't wait for changes to come from the top, you have to initiate them yourself, here and now. If social organizations start focusing on

this, then things can change considerably...Our goal is to ensure that in two or three years the local administration will support these programs – harm reduction, syringe exchange, and the community center.

The agency director in Sloviansk proposed that HIV prevention in Ukraine should be carried out by a "tandem of forces" coordinated between the state and the "third sector" (i.e., social organizations), with each of these actors "having equal weight." He was convinced that too much power (and resources) should not be bequeathed to the national and city governments, citing a history of state misuse of resources in the HIV prevention sphere. If the agency director in Poltava advocated an eventual "state takeover" of HIV prevention efforts, the Sloviansk director had a rather opposite view. He said: "The state is trying to take over this sphere, but NGOs shouldn't let it." The implication was that the state's only interest in HIV prevention was monetary, and he warned of a situation where (as had happened in the past) the state would gladly appropriate the resources offered by international donors without ever implementing much-needed HIV prevention programs.

In contrast to these models based on a belief that the state can be reformed - however slowly - other agencies have consigned themselves to working in a context in which the state is not a reliable partner in HIV prevention efforts. As a result, they do not attempt to form sustainable partnerships with the state. For instance, although some staff members at the HIV service agency in Mikolaiv voiced their convictions that the Ukrainian state, with its access to "resources" and "power," should be responsible for HIV prevention, there did not seem to be a strong expectation that it will ever actually take on this responsibility. Indeed, when asked to elaborate on the state's current HIV prevention programs, informants could rarely point to anything beyond a few rudimentary educational programs in schools. Apart from a few overlaps between medical staff at the local AIDS Center and the agency, compared with other organizations in our study this agency did not appear to have forged many strong partnerships with state actors or institutions. Instead, agency staff perceived the role of this HIV service organization as primarily one of supporting clients and enabling clients to help themselves and keep themselves safe. This view of the state as unable to be reformed and the work of HIV prevention organizations as apolitical reflects trends seen elsewhere in Eastern Europe (Owczarzak 2010).

The tenuousness of these hopes for state-level reform and formal commitment to HIV prevention has been dramatically exposed by the ongoing conflict in eastern Ukraine. In a November 2014 interview, the director of the agency in Sloviansk emphasized that today, in a context of post-conflict lustration (screening new officials for involvement in the former regime), tackling issues related to drug use and HIV is not at all an attractive political platform for local politicians jockeying for power. Indeed, the agency director reported that the recent armed conflict - during which Sloviansk was occupied by pro-Russian forces of the Donetsk People's Republic (DPR) from April 12 to July 5, 2014, and was the site of heavy fighting disrupted hard-won cooperative relationships the agency had managed to forge over the years with city law enforcement, the city administration, and other political players. If the agency previously enjoyed a sense of security in carrying out its prevention work with people who use drugs, today it operates in an atmosphere of mistrust, fear, and violence. (Owczarzak, Karelin, and Phillips 2014) Lack of formal commitment by the state to work with agencies, enforceable laws that protect drug users, prevention efforts such as needle/syringe exchange and OST, and a knowledgeable public service sector undermine the HIV prevention efforts within the third sector. The current situation highlights the previously observed nature of state-NGO partnership in Ukraine's HIV-related sphere as based around individual relationships rather than broad-based, system-level commitment and support (Bojko, Dvoriak, and Altice 2013).

### Responsibility and authority

These varying attempts to reform or align with the state raise questions regarding who has the legitimacy and authority to work on these issues. This tension was highlighted by the director of one agency, who emphasized that NGO staff are professionals with expert knowledge that the state failed to recognize:

Of course the state should rely on NGOs more; they don't utilize our innovations. For some reason they have the impression that NGOs are made up of non-professionals, while the state workers are all professionals; [they think] that NGOs are made up of just some random people. [They don't realize] that we have been working [in this sphere] for 15 years, our staff has higher education, and we do serious research. Somehow they don't get it, that it would make sense to utilize this potential, these innovations.

Another agency worked to integrate its professionals and experts into state systems: social workers from this organization are officially employees of the local AIDS Center; the agency runs a shelter for drug users that is partially funded by the local government; and the NGO has implemented joint projects with law enforcement. Becoming part of the state system legitimizes and formalizes their status as experts and the state, as manifest at the local level, acknowledges this expertise.

HIV-related NGOs further legitimize their status as knowledgeable experts and increase the credibility of the state by integrating state-employed medical personnel into agency-based prevention work with drug users through projects that train state employees (medical personnel, law enforcement, lawyers) in HIV prevention and other work. Agency staff also emphasized the positive effects that their "training" of medical personnel has had for the generally improved health care now provided to their clients who are living with HIV. The agency director in Poltava summed up this view: "Today there is not blanket discrim-

ination of HIV-positive persons in the health-care system, but there are still some individual doctors and nurses who give them trouble." Responding to discrimination of people living with HIV and AIDS in the health-care system, many of the HIV service organizations have forged excellent partnerships with medical personnel at the local AIDS Centers (after all, these NGOs and AIDS Centers often share employees), a situation which usually works to facilitate better trust between patients and medical professionals, and more compassionate and timely medical care for the agencies' clients. Some agencies have identified particularly cooperative and "enlightened" doctors to whom they refer clients. One outreach worker in Sloviansk, for example, refers all of her clients with serious medical problems to the same general surgeon in the city, who has become an ally of the HIV service organization.

While HIV-related service providers face numerous barriers to providing necessary prevention programs for substance users such as OST and needle/syringe exchange, the state plays a more visible role in HIV treatment and care. Indeed, when we asked agency staff to describe the state's HIV prevention efforts to us, they usually mentioned HIV-related health-care services (i.e., services for people living with HIV and AIDS), not prevention programs. The greater involvement of the state in treatment is reflected in the distribution of national AIDS funding, of which more than 60 percent is spent on care and treatment. (Ukraine 2010) Many respondents pointed out that whereas several years ago the Ukrainian state only covered 20 percent of the costs to provide antiretroviral therapy to people living with HIV (with foreign donors covering the rest), today the state covers most or all of these costs. More broadly, a social worker at the agency in Odesa pointed out that "HIV-AIDS care really is free here. That is something you cannot say for any other health services [even though officially state health care is supposed to be free of charge]."

All of the agencies worked closely with city AIDS Centers, and referred to the AIDS Centers as evidence of the state's engagement in HIV-related services. Many respondents from HIV service or-

ganizations mentioned that the state social services (manifest, for example, in institutions such as local Centers for Youth and Families) were marginally involved in a few HIV prevention efforts, but they evaluated these efforts as inconsequential and ineffective. One staff member of the Sloviansk agency described state social services as "shriveled up and

uninterested." Similarly, the agency director in Poltava declared that state social services are practically non-functioning and have become irrelevant, joking, "You can go ahead and hold a memorial service for them." The director of the Sloviansk agen-

When patients have visible abscesses or display signs of intoxication, they are frequently provided fewer services, receive less attention, or are simply turned away from the hospital.

cy put it thus: "The state does absolutely nothing in ... prevention ... all they do is print a bunch of pamphlets that people throw away." When asked whether the state has reacted to the changing epidemiological pattern of HIV transmission in the country (injecting drug use was formerly the main transmission route; now it is heterosexual sex), the director of programs for people who use drugs at the Odesa agency jokingly responded, "Yes, they've reacted – they doubled the price of condoms!" Her exasperated comment crystallized the assessment of many of our interviewees from HIV service organizations that the state's HIV prevention efforts are inadequate.

### Serving the public in the public sector

Despite this more engaged state sector in the area of HIV treatment and care, significant problems remain with getting people living with HIV and AIDS, many of whom have histories of drug use or engagement in sex work, the necessary care they need. For decades, these populations have been the targets of violent repression, marginalization, and neglect. These negative experiences extend to medical encounters as well. The agency psychologist in Mikolaiv said that his clients' medical conditions or engagement in commercial sex work is indicated on their medical cards and affects

how they are treated, adding, "Some health workers put on four pairs of gloves before examining them." This is especially true in emergency rooms, where clients are shunned and abused by medics ignorant about injection drug use and HIV. When patients have visible abscesses or display signs of intoxication, they are frequently provided fewer

services, receive less attention, or are simply turned away from the hospital.

People living with HIV and AIDS are also sometimes denied medical treatment based on their status (also marked – in contradiction to confiden-

tiality laws - on their medical cards and records). Agency staff described HIV-positive clients' encounters with medical services as frequently traumatic and inhumane. The resource center director at the Odesa agency related the case of a single mother of three who was living with HIV and was refused a life-saving operation: "The only surgeon in the entire Odesa region who could do it ... refused. He said, 'How can I operate on her when my nurses are afraid to touch her? Who is going to change her bandages?" Furthermore, people living with HIV and AIDs who are known to inject drugs may face double discrimination. The director of the Poltava agency gave an example: "In terms of access to medical and social services, for example, it is easier for an HIV-positive person who is not a drug user to get a [disability] pension [than it is for a person living with HIV and AIDS who also uses drugs) ... Because they [the Medical Social Expert Commission] think, sort of, 'It's his own fault', and they can just throw him out [of the office], thinking that no one will stick up for him."

### Re-arranging state-citizen relationships

When asked what they viewed as the ideal HIV prevention program, service providers often described a complex strategy that would address structural and socio-economic factors that contrib-

ute to HIV risk. They also advocate for a greater sense of collective responsibility toward fighting HIV, rather than relegating concern to NGOs or state institutions. Similarly, they call for intersectoral approaches that include social policy, health, and education to address this complex problem. The current situation is a long way from these ideals. In some ways, international donor organizations have facilitated state atrophy by relegating the most challenging issues related to stopping HIV to the third sector. The continued mistreatment within the public sector of people living with HIV, drug users, and other marginalized populations at risk for HIV highlights that the state in some ways has been absolved from its responsibility to serve all citizens, even the most challenging.

With the view that public-sector institutions such as health-care systems cannot be reformed or only too slowly, NGOs – with the support of foreign donors – may create parallel services and systems of health-care delivery (Pfeiffer 2013). Although there have been attempts at collaboration, in Ukraine NGOs have taken primary responsibility for addressing one of Ukraine's most urgent public health crises. NGO staff and directors' visions of a reformed state that would either take over HIV prevention efforts or at least be a reliable collaborator recall the concept of the "would-be state," in which the power and legitimacy of the state reside in yet-to-be-realized achievements (Frederiksen 2014). At the same time, the continued active presence

of NGOs filling public-sector roles of health-care service delivery further undermines and weakens the state as these same NGOs attempts to reform and strengthen the state (Batley and Mcloughlin 2010). The stakes here are high, as the Global Fund is expected to withdraw its long-time support from Ukraine in the very near future. Without this major source of program support (the NGOs in our study all received at least 45 percent of their financing from the Fund), in all likelihood prevention programs will stall, and the HIV epidemic will continue, as happened in Russia after the Fund's exodus from that country in 2009 ("The Future of Harm Reduction Programmes in Russia." 2009).

In this context, who will ultimately be responsible for HIV prevention and care, and the balance between the state and the third sector in this arena, remains to be seen. As Phillips (2008) argues, NGOs in Ukraine are a forum in which new social politics are contested and reimagined (Phillips 2008). The NGOs we work with all emerged in the early 1990s in response to the country's HIV, drug use, and related health crises. Through their activism on behalf of people at risk for and living with HIV, NGO staff re-imagine what a reformed Ukrainian state might look like. While some NGOs strive to insulate themselves from the state, others engage with it directly in order to create a state that is more inclusive of the most marginalized sectors of society.

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