Surviving war and growing authoritarianism: How to ensure sustainability of civil society and community-led responses by people affected by HIV & TB and key populations

A communique from the Regional Consultation, During and after the war: rethinking the role of regional community networks of PLHIV and key groups and other civil society organizations.

Vilnius, June 29 – July 1, 2022

Introduction and summary

The purpose of this communique is to build a common vision among communities, civil society, donors and other national and international stakeholders about the role of community-led initiatives in the face of the war and about what is needed for their sustainability. The large-scale aggression of the Russian Federation against the sovereignty of the Ukrainian government and people that started on February 24 has caused devastating loss of life, displacement of people, massive human rights violations, trauma, disruption of access to treatment and basic medical and social services and a myriad of harms which heighten vulnerability to HIV, TB and other infectious diseases and challenge care.

From June 29 to July 1, 2022, fifty representatives of: regional networks of people affected by HIV & TB and key populations (KP) (including: people who use drugs; sex workers; men who have sex with men; and lesbian, gay, bisexual, transgender and intersex (LGBTI) people as well as prisoners and migrants); civil society networks, UNAIDS, The Global Fund, experts from fields of HIV, TB, human rights and security attended the Regional Consultation, "During and after the war: rethinking the role of community networks of PLHIV and key groups and other civil society organizations," in Vilnius, Lithuania to facilitate regional unity and preserve the influence of communities of people affected by HIV and TB, key populations (KP), community-led networks, and civil society organizations (CS). This communique, finalized in September 2022, reflects the outcomes of that meeting and is signed onto by the organizers and participants in the meeting listed at the end of the document. (signatures at the end)

The war is a harbinger of tectonic change for Ukraine and neighbouring countries, accelerating changes that had started before the war and also catalysing new changes. The region saw itself (and was seen by others (including the donors, international organizations, and policy makers) as united, but it is currently fragmenting rapidly - breaking into sub-regions with varied geopolitical interests. Each of these sub-regions is faced with unique challenges and tasks related to: the humanitarian crisis; HIV, TB and responses; human rights; economics and funding. Groups led by people affected by HIV & TB, key populations and civil society organizations are uniquely positioned to respond to these challenges and have rapidly evolving needs.

Key recommendations:

1. Donor support will be essential for civil society and community-led organizations to fulfil their potential in responding to crisis (by providing services, monitoring the rapidly changing situation on the ground and advocating for evidence- and human rights- based responses.)

- Donor flexibility in meeting emerging support needs and providing support for sustainability of civil society and community-led organizations will enable a practical and agile response.
- Community-led responses that are having a central role in resilience must be documented in order to garner further support, to share new good practices, and to counter stigma and discrimination by showing the agency of groups of people who are usually stigmatized and marginalized.
- 3. Organizations and activists face new security risks and should be provided with technical and financial support to ensure their physical, mental and digital security to help them avoid arrest and imprisonment for their views and support of stigmatized and criminalized communities. Safety and security of communities they serve must be ensured.
- 4. Pro-democracy reforms that may rise in some countries of the EECA region in response to the threat of authoritariansm, should be leveraged, where possible, to advocate for long-needed changes, such as, decriminalization of KP; more people-centered health services; funding of community-led health, and mental and social services.
- 5. Partners should acknowledge intensifying sub-regional differentiation (as that the fragmentation of which had begun before the current crisis is accelerating) and must address the differing opportunities and needs including safety needs in the different sub-regions.
- 6. Country and international partners should recognize, that, in the more fragmented region, Regional Networks will have an even more important role to play in maintaining and building solidarity and cooperation between activists, professionals, and decision-makers in the different countries.
- 7. The crisis has just begun. There are rapid changes underway and much is unknown about the future. This consultation was just a first step in maintaining and building the solidarity needed to move ahead common agendas for health and rights.

Key Problematic Areas

The humanitarian crisis

Russia's invasion of Ukraine has led to a devastating humanitarian crisis, rife with loss of life; injuries; trauma; destruction of infrastructure and disruption of health and social services; displacement of people and a myriad of other health and social problems. As of the 7th of September, 7,154,448 million refugees from Ukraine have fled to Europe and another 4,005,806 people voluntarily and involuntarily were displaced to the Russian Federation¹. As of August 2022, 6.97 million Ukrainians have become internally displaced people (IDP), ²[]. It is estimated that 3.8 million Russians have fled the Russian Federation. ³People affected by HIV and TB and other key populations (KP) are among those who often require evacuation, safe housing, food and other very basic needs to be addressed (in addition to their healthcare needs related to HIV, TB and or drug dependence.) According to the results of a rapid assessment among 36 Ukrainian NGOs of the needs of their, 100% of them required food; 94.4% required hygiene kits and 08.6% required temporary residence. In Ukraine and other countries, measures have been taken to provide access to antiretroviral medicines (ART), drug-sensitive and drug-resistant TB treatment, and opioid agonist therapy (OAT).

¹ [https://data.unhcr.org/en/situations/ukraine]

² https://displacement.iom.int/ukraine

³ https://fortune.com/2022/08/20/russia-brain-drain-young-russians-leaving-after-ukraine-war-putin/

Advocacy by CS and community-led organizations has helped make that happen. Stigma and discrimination can inhibit KP, people with TB and PLHIV from accessing services for IDP and migrants. There have been cases of KP being denied access to shelter, for example. Community-led and civil society organizations from the fields of HIV and TB have continued to serve KP, and have also contributed to the humanitarian response, leveraging their physical, financial and human resources to serve the general population, both in Ukraine and in refugee-hosting countries.

HIV, TB & health responses

The war will increase vulnerabilities to HIV and TB and challenge the provision of services in Ukraine, in countries affected by the refugee crisis, and throughout the region, where economic and social upheaval and changing patterns of migration are felt. Displacement, unemployment, poverty, mental health strain, and refugee status all influence the demographics of vulnerability to both HIV and TB and also the needs of users of services. At the same time, services can be very strained. In Ukraine, displacement of people left services understaffed, and available staff are overworked, traumatised, suddenly performing new tasks at great personal risk, and often at-risk of burnout. At the same time, reforms undertaken in Ukraine prior to the war, to integrate services for KP, people with TB and PLHIV into the drive for Universal Health Coverage (UHC) are contributing to resilience during the war. In the territories with active military actions, death, destruction of physical resources, breakdown of logistics systems are leaving people without services and adequate information on the situation on what is going on there is unavailable. In territories receiving large numbers of IDPs, availability, accessibility and quality of services require further support. In countries receiving refugees and migrants, services are challenged: they are overcoming language and cultural barriers and working to secure adequate supplies of medicines and commodities for new clients. Emergency grants from the Global Fund in Ukraine, Romania and Moldova have helped to address the strain, but longer term solutions with greater geographic scope are needed.

Human rights and advocacy

Human rights were already fragile in the region and the war plus growing authoritarianism have made the situation much worse. The incredible violence of war, including sexual and gender-based violence, will strain human rights mechanisms and growing militarization and polarization can lead to internal conflicts as well as repression of civil disobedience. Rising authoritarianism gives way to beliefs, policies, and practices which lead to: violence; human rights violations; growing stigma and discrimination; non-evidence-based health policy; erosion of freedoms of expression, association and assembly; attacks and harassment of human rights activists; use of technologies for monitoring and harassment (security cameras, data collection, etc.); and growing police violence. Rights defenders are under attack in some countries leading them to need their own rights defended and also leading to people fearing getting involved in defending rights. The human rights profiles of different countries are in flux as geopolitics evolves and countries' politics and values sway under the interests of differing spheres of influence.

Economics, funding, and advocacy:

The war is straining economies which were already feeling the slump caused by COVID-19. Ukraine's economy and the economies of other countries in the region have been hit heavily by the war and the related sanctions. The influx of refugees and increased needs for socioeconomic support as well as growing demands from the health and social protection systems are coming at this tough time. Due to growing inflation and instability of currency exchange rates, the costs of services, logistics and

commodities, including medicines, are rising unpredictably. For example, in Moldova, the Medical Devices Agency formally announced that it expects that medication prices will increase by a further 8-10% by Autumn.⁴

As expenditures on defence are prioritized, funding for social and health programming may decline. Economic contraction and accompanying inequalities will likely disproportionately affect KP, people with TB and PLHIV as well as state funding for state social and health services.

Community and civil society uniquely positioned to respond

Unlike in mature democracies, in many countries in the region, there has not been the luxury of living with strong and functioning state institutions. Civil society and groups of PLHIV, people with TB and KP have played an essential role in pushing for evidence-based and human rights-based policy and practice and have also mobilized to provide services when state services fell short or where state services might alienate stigmatized, discriminated and criminalized people. In these times of crisis, these groups have mobilized to quickly respond to new vulnerabilities and threats. In Ukraine, HIV, TB and KP groups have stepped up to provide support to the general population. In refugee-hosting countries, HIV, TB and KP activists have been instrumental in linking refugees with health and social protection services, bridging the access and language gaps. For activists and network representatives, security, physical, mental and digital, has become very relevant.

Regional Community and Civil Society Networks

Regional networks of PLHIV, KP, and civil society organizations are facing a host of new challenges since the war started. They have a critical role to play in helping their members and partners counter new threats and live up to their potential in protecting the rights and health of the people they serve in a time of crisis.

The war has led to growth of physical and electronic barriers between people. People from the region are facing new difficulties in obtaining visas for travel to the EU and travel to Ukraine, Belarus and Russia is nearly impossible. Travel and logistics and supply routes in other countries in the region have also been disrupted. Growing authoritarianism in many countries jeopardises human rights and the security of activists. Russians can be arrested for even mentioning the war and its activists are fleeing. With travel being more limited and with people accessing increasingly divergent sources of information on the internet, communication and "common ground" is reduced. This, in some cases, has led to a growth in a gap in the values held in the hearts and minds of activists. In relation to Russia's invasion of Ukraine, they faced polarization among their membership and had to grapple with taking a stand and working to unite people around their original missions. Different networks took different approaches and, while some are willing to support members and communities in the Russian Federation, in other cases, members were expelled or resigned voluntarily. The main lesson learned from this experience was that ignoring the problem will not solve the conflict. A positive practice was to have difficult discussions and preparation and publication of an official position on behalf of the network.

 $^{^4}$ http://www.canal2.md/news/dragos-gutu-din-toamna-moldovenii-vor-plati-mai-mult-pentru-medicamente_149082.html

Conclusions and recommendations

Communities, civil society, donors and other national and international stakeholders must evolve their responses to support community- led and civil society -led responses and their regional networks to adapt to new challenges. Below is a set of key recommendations as well as detailed recommendations related to: the humanitarian crisis; HIV, TB and health responses; human rights, economics & funding.

Responding to the humanitarian crisis;

- 1. Donors and technical support providers must support community-led responses and civil society to advocate for and provide services to people affected by HIV and TB, KP, and their close ones among migrants/refugees/IDP, as well as document results of their work.
- 2. Community-led groups and civil society must engage in new partnerships, for example with:
 - a. social services in countries receiving migrants and refugees;
 - b. housing works;
 - c. faith-based organizations.
 - d. Humanitarian aid organizations;
- 3. Community-led groups and civil society must strategically engage with the UN humanitarian clusters to ensure access to humanitarian funding so that their needs are addressed and their capacities to contribute to the response are leveraged.
- 4. Donors and technical support providers must support community-led groups and civil society to develop new knowledge and skills concerning:
 - a. provision of services in humanitarian crisis settings using the experience from humanitarian responses in other countries, like for example, Armenia & Azerbaijan.
 - b. refugee support and humanitarian mechanism of the EU countries;
- 5. Donors and technical support providers must support community-led monitoring and advocacy to address the rapidly changing needs of people affected by HIV, TB and KP.
- 6. Donors and technical support providers must support the documentation of the community-led responses that are stepping up to contribute to the humanitarian response, in order to support the advocacy and fundraising efforts needed to further leverage the unique resources that they bring to the scene.

Supporting HIV, TB and health programming

- Governments must support integrated people-ce ntered services to expand the packages of services they offer to address mental health, housing, employment to address new needs caused by trauma and displacement. Health donors must expand the packages they offer to add mental health and additional social services.
- 2. Countries that are receiving refugees and migrants must take care to ensure that their work to achieve UHC addresses the needs of migrants and refugees.
- 3. Partners must continue to seek solutions for ensuring access to services in active conflict zones, newly-occupied territories and non-government controlled areas.
- 4. Countries should make permanent the innovative solutions that eased access to services during the COVID-19 pandemic , such as: self-testing; task-shifting enabling community-led groups to

- deliver medicines or receive licences to provide testing, etc.; or providing OST patients 30-day supply of their medicine (which is now both policy and practice in hotspots in Ukraine).
- 5. Donors, community-led groups and civil society must support documentation, research and advocacy showing that civil society and community-led services are integral to optimization and integration of services.
- 6. Countries should implement digitalization of medical information systems for both patients and medics such as on-line medicine, and, digital patient maps, digital health systems, online clinics; digital applications, use of artificial intelligence capabilities add to efficiency and remote access to information. Efforts to digitalize must be mindful of the fact that many KP do not readily have access to digital programming or are fearful that accessing it could lead to a violation of their confidentiality.
 - a. Protecting human rights within the digitalization approach, including rights of key populations, is a must.
 - b. Security measures, including confidentiality of data will be essential so that it is not used to harass or persecute people
 - c. The locus of information should be decentralized so that a problem at one site would not lead to loss of information.
 - d. Blockchain might be used for security.

Promoting and defending human rights

- 1. Donors, technical support providers and regional networks must acknowledge the need to differentiate approaches to safely engage in advocacy and defending human rights in countries in different spheres of influence have increasingly divergent values such as those and different approaches are needed to ensure effectiveness and safety of work for countries that are European Union (EU) members, EU accession countries, and those which are members of the Eurasian Customs Union (EACU).
- 2. Community-led groups and civil society in countries responding to the threat of authoritarianism with with pro-democratic changes should leverage the opportunity to move forward on human rights issues such as decriminalization for example.
- 3. Advocates in countries must enhance efforts to win "hearts and minds" in the general population and activist groups should reach out to new partners like trade unions, religious groups etc. to make their case for democracy, health and for human rights.
- 4. Donors, countries, community-led groups and civil society must ensure that the sanctions applied to Russia and Belarus do not hinder access to essential medicines and services.
- 5. International partners must be sensitive to the security of human rights defenders in the field.
- 6. Community-led groups, civil society and their partners must be proactive in these times of growing authoritarianism to prevent the passing of laws that constrict rights rather than wait until those laws are passed and work to defend rights in the more challenging legal setting.

Economics & funding

- 1. Community-led groups and civil society must, as countries establish new budget priorities in response to the rapidly changing situation, advocate to ensure funding for services needed by KP and people affected by HIV and TB and donors should support them to do it.
- Community-led groups and civil society must actively participate in planning for Ukraine's
 recovery to ensure that the needs of KP and people affected by HIV and TB are met and that the
 capacities of community-led and civil society organizations are leveraged in the recovery
 process.

- 3. Community-led groups and civil society and their partners from governmental institutions must advocate for their governments and parliaments to secure domestic health funding, which might be under threat due to the challenging macroeconomic climate and competing interests.
- 4. Community-led groups and civil society and their partners from governmental institutions should remind decision makers that efficiency in health and social support systems can be built through integration of services and leveraging the potential of community-led initiatives.
- 5. Community-led groups and civil society must try new and alternative sources of funding such as crypto-philanthropy which offers:
 - a new form of more effective organization of communities and like-minded people;
 - b. broad involvement of new participants;
 - c. informing a wider range of people about the problems of HIV/AIDS;
 - d. attraction of alternative sources of financing;
 - e. the use of modern technologies to solve health problems
- 6. Community-led groups and civil society and their partners from governmental must apply Intellectual Property flexibilities and other ways to reduce prices for essential products in the face of inflation to lower medicine prices and enable more efficient use of available resources.

Support community-led responses and civil society

- 1. Donors, technical support providers and partners in countries must redouble efforts to ensure that the voices of KP, PLHIV, people affected by TB and civil society be heard as societies redefine priorities in this time of crisis.
- 2. Community-led groups and civil society (with the support of donors) must document and promote the role that community-led and civil society groups have had in the resilience of health responses, showing how they innovate to solve new problems often more quickly than government institutions.
- 3. The good examples from Ukraine and Moldova of community-led organizations mobilizing to support not only their own communities but the general population should be popularised to illustrate their value to the general population.
- 4. In quickly changing situations, community led monitoring (CLM) can provide critical information needed for decision making in real time. Support of CLM is essential to building efficient responses.
- 5. Advocates should emphasise that mechanisms for greater meaningful involvement of PLHIV and KP in the design, implementation, monitoring and evaluation of interventions as well as participation in high-level decision-making forums is inherently democratic and bolstering it, not only makes for more effective programming but is a way to push back against authoritarianism and protect democracy.
- 6. Clear efforts must be made to address growing security needs of groups of PLHIV, people with TB, KP and civil society.
- 7. Organizations must work to ensure physical safety of their staff and have emergency exit strategies to have a plan for what to do should they have to evacuate their staff if needed. With growing authoritarianism, the personal security of activists must be ensured (not only for activists from Ukraine, but also from other countries of the region, Belarus, Kazakhstan, Russia)
- 8. Mental burnout must be addressed as activists are often working without rest or breaks, are living with the war related trauma or living in a state of fear either from war or from working in

- an authoritarian regime. There must also be preparedness for longer term post-traumatic disorders.
- 9. Organizations must upgrade digitization for security and efficiency. Use of blockchain can help secure anonymity and security and decentralization of the physical location of information.
- 10. Organizations must take care to preserve institutional memory.
- 11. Organizations should have plans for addressing disruptions in access to internet that is free of state control.
- 12. Organizations need security assessments and tailored policies and practices using existing support from specialized organizations.
- 13. Donors must become more flexible:
 - a. Offering stronger support for networking, community-led research, advocacy and communication programming (that helps change hearts and minds)
 - b. Support community-led monitoring to detect opportunities for intervention
 - c. Allow quick adaptations to and reprogramming of HIV, TB and social services in response to the changing war/humanitarian context
 - d. Enable adjustments of budgets in response to inflation

Supporting regional networks

- 1. Regional networks have an important role in maintaining solidarity around core values of human rights and universal health coverage
 - a. Regional networks can lean on their mission and value statements to unite people around their common values (based on empathy, humanism, democracy, freedom, human rights, opposition to authoritarianism, evidence-based policies and practices).
 - b. Regional networks must be supported to work to address new physical barriers (such as more limited ability to travel between countries) and new electronic barriers (as social networking between countries becomes more limited) between their members in different countries.
 - c. They should also consider securing multi-entry visas for activists, especially for their members in countries with growing authoritarianism.
- 2. Regional networks may need to adjust their membership criteria to enable continued participation of new diasporas in migration, outside the region (ie. suddenly having members that live in the EU or other countries outside of their geographic region of focus)
- 3. Regional networks may need to discuss their common languages of communication. With Russia's continued colonization policy, the Russian language might become unacceptable in some countries and forums, despite being well-understood by most activists.
- 4. Regional networks will have an essential role to play in supporting community-led monitoring and promoting community and civil society -led Innovations and "life hacks" for dealing with new problems arising they are in a unique position to enable their membership to detect them and share them.
- 5. When the time comes for reconstruction in the region after the war, the regional networks will have an important role and lessons from the Balkan region for example will be important to learn from.

Organization	Signed
Eurasian Coalition on Health, Rights, Gender and Sexual Diversity (ECOM)	Vitaly Djuma
Sex Workers Rights Advocacy Network (SWAN)	Stasa Plecas
Eurasian Network of People Who Use Drugs (ENPUD)	Olga Belyaeva
Eurasian Harm Reduction Association (EHRA)	Ganna Dovbah
Health Advocacy Coalition (HAC)	Sergii Dmitriiev
International Budget Advocacy Hub (IBAH)	Maxim Demchenko
International Treatment Preparedness Coalition (ITPC) EECA	Denis Godlevskiy
TB Europe Coalition (TBEC)	Paul Sommerfeld, Chair of TBEC
Positive Women Ukraine	Olena Stryzhak
100% Life Ukraine	Dmytro Tyhach
Regional Expert Group on Migration and Health	Daniel Kashnitsky
Eurasian Movement for the Right to Health in Prisons	Oleksii Zagrebelnyi
Central Asian Union of PLHIV	Nurali Amanzholov
Eurasian Women's Network on AIDS (EWNA)	Svitlana Moroz
Teenergizer	Yana Panfilova
Positiva Initiativa (Moldova)	Ruslan Poverga
Drug Policy Network South East Europe	Milutin Milošević

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