A Europe free of AIDS, TB and viral hepatitis - and no one left behind

Joint Statement -*As part of Thematic Networks led by EU Civil Society Forum on HIV/AIDS, Hep and TB*

1. Background

1.1. Introduction

The EU Civil Society Forum (CSF) on HIV/AIDS, tuberculosis (TB) and viral hepatitis brings together community and civil society networks (please find full list here) to inform European and International Health agencies, to support joint actions, and to advance policies and interventions that improve the health and well-being of communities that are most affected by these conditions.

With the European Health Policy Platform Thematic Network on HIV/TB/VH/STIs, the CSF held two webinars addressing **Standards of Care: HIV, VH, and TB:**

- Good Practices and Ensuring Prevention & Care for People on the move;
- Eliminating Stigma, Discrimination and Criminalisation of Key Populations.

1.2. The HIV, TB and Viral hepatitis health gaps

The Global AIDS Strategy 2021–2026 and the World Health Organization (WHO) call for renewed focus on viral hepatitis, HIV and TB epidemics within the European Region. As inequalities drive the HIV/AIDS epidemic, ensuring that disadvantaged people can access HIV services is crucial to meeting these targets.

The European region is diverse in terms of epidemiological burden, countries in eastern Europe and central Asia face high burdens of viral hepatitis, HIV and TB.

For **HIV/AIDS,** the Global strategy prioritises societal and service enablers to be achieved by 2025. These are called the 10–10–10 targets:

- "Less than 10% of countries have punitive legal and policy environments that deny access to justice.
- Less than 10% of people living with HIV and key populations experience stigma and discrimination.
- Less than 10% of women, girls, people living with HIV and key populations experience gender inequality and violence."

The 2022–2030 WHO Europe strategy on HIV and viral hepatitis draws attention to the region's being off track to meet the 2030 95/95/95 target for HIV. This implies that 85.7% of people with HIV know their status and are virally suppressed. As of 2020, only 60% did.

Dealing with infections and dealing with cancers intertwines. For **viral hepatitis**, out of 14 million people with chronic hepatitis B and 13 million with hepatitis C, only 19% and 24% respectively know their status. In 2020, 90,000 deaths from liver cancer (out of a total of 107,000 liver related deaths) were recorded in Europe. This signals the scale up hepatitis B vaccination and improving screening and treatment access for both conditions.

The number of people with **tuberculosis** who are co-infected with HIV is still increasing. TB accounts for about 70,000 deaths a year regionally. The COVID-19 epidemic saw high mortality in people with TB and resulted in an increase in TB deaths exacerbated by COVID; the recovery from this uptick in mortality has taken longer than in other regions. The TB plan calls for a decrease relative to 2020 of TB mortality of 65% by 2025, a reduction in TB incidence by 50%, and an increase in successfully treated MDR-TB of 80%.

Migration and displacement of people due not only to the Ukraine war but also to other armed conflicts, political instabilities, and natural disasters in other parts of the world brought new people with new needs into the EU and neighbouring countries and demand new answers.

The EU member states are committed to work towards the 2030 Sustainable Development Goals. The European Commission supports member states to achieve them. While countries are responsible for

their health system, the EU has policies and financial and technical support tools to complement member states' actions and to support cooperation across countries.

2. Improving healthcare, including cross-border

2.1. Improving standards of care and their delivery

The great variation in the quality of and access to care delivered by clinics in Europe needs to be addressed. Prevention and treatment approaches need to evolve to meet the needs of populations at risk and patients in a climate of financial limitation.

Challenges

- **Changing clinical demands and care** resulting from an ageing population of people living with HIV, retiring first generation of HIV nurses and physicians, create a need for broader education with increased migration refugee flow with various needs, new treatment strategies based on long-acting regimens.
- **Unavailability of TB Medicines** results from pharmaceutical companies' reluctance to incur the costs of registration of new drugs in the EU/EEA/UK given the small size of the local TB market. These include child formulations of the regular TB drugs – available elsewhere in the World for the past 10 years- and rifapentine, important for treating latent TB and a component in the first WHO-approved four-month regimen for drug-sensitive TB.
- **Lack of prioritisation of viral hepatitis** results insufficient screening and HCV treatment programmes.
- **Under and insecure funding basis of civil society and community organisations** which provide essential services to key populations in the HIV, TB, viral hepatitis response. They have also been mobilised in the response to Mpox and COVID-19 outbreaks and in humanitarian contexts such as those created by the war in Ukraine and in other parts the world.
- **Peer-navigator programmes** have been of proven worth in working with criminalised and stigmatised people in other parts of the world but are currently underused in the European context.
- **Barriers to decentralised testing** enhance the uptake and diagnosis of HIV and STIs, WHO recommends the integration of decentralised and demedicalised service delivery, peer-led programmes, self-sampling collection, and the use of digital platform. However, scale up is hindered by lack of or poor implementation of legal frameworks, diagnostics licencing and registration along with cost and stigma barriers.
- **Lack of implementation of universal health coverage** leaves many uninsured and undocumented people without access to prevention tools and care.

Good and promising practices

- **Defining, auditing and re-auditing standards of care and prevention** enables individual practitioners, clinics, and regional or even national healthcare systems to measure their performance both against agreed targets and against each other (and therefore against an average). For instance, EACS and ECDC audited of standards for viral hepatitis screening, vaccination, treatment for people diagnosed with HIV in Georgia, Germany, Poland, Romania and Spain. The first audits uncovered widely differing areas of practice not only between countries but between individual clinics. The re-audit two years later found improvements in many areas.
- **Participatory approaches can play a key role in defining standards of care and prevention.** For instance, the European Clinical AIDS Society (EACS) and the European Centre on Disease Prevention and Control (ECDC) are collaborating with healthcare professionals, clinicians, communities and partners to define standards of care (including prevention) and an audit tool which can be used in the various participating countries.
- Community-based organisations and civil society can enhance **decentralised and outreach testing.** They are key players in testing uptake and in advocacy in relation to enabling policy, regulatory approvals, and gaining state funding/buy-in of proven and innovative screening approaches, such as rapid testing, self-testing, self-sampling, screening Hand-held X-ray equipment, enhanced by AI.
- **Digital platforms** are promising and adaptive complementary tools. For instance, *OneImpact* is used by TB services in several countries and is especially effective in Ukraine, where TB services continue to work effectively. Over the last year, TB People of Ukraine, a survivor-led organisation using *OneImpact*, received 1800 requests relating to treatment problems, discrimination, money difficulties and rights violations. The organisation was able to assess these issues individually and used them as evidence in advocating for legislative and procedural changes nationally.
- **Standardised Packages of Care in TB provided by civil society** can serve as frameworks for public payers to contract CSOs for defined services. This is the case of Standardised Package of services developed by the TB Europe Coalition (TBEC), PAS and WHO, with the support of the Global Fund TB-REP2 programme, developed. It also opens the route to sustainable and regular funding for these community-based services. This is especially important in countries that are not eligible for Global Fund support and are reliant on domestic public funding.
- **Making child formulations of the regular TB drugs and Rifapentine available and accessible** needs action urgently from EU, governments, civil society, regulators of medicines and pharmaceutical companies.
- **Georgia viral hepatitis elimination programme** reduced hepatitis C prevalence through universal testing, treatment, and door-to-door screenings. So far, two-thirds of Georgia's population has been screened, with 98,725 found to have active hepatitis C. Of those, 76% started antiviral treatment, and 99% are considered cured. Hepatitis C prevalence has dropped by 67% since 2015.
- **The HCV programme in prisons in Luxembourg** provides healthcare to people in prisons, including testing, treatment, and vaccination against hepatitis A and B. The nurses provide

counselling and follow-up appointments for released people and work with wardens to prevent disease transmission in prison through condom availability and needle exchange programmes.

2.2. Cross-border care and access gaps for displaced persons, refugees, and other migrants in precarious situations

It is critical to ensure continuity of care for all people displaced access testing, prevention, treatment, and care. Ukraine has a high burden of HIV, TB, multi-drug resistant TB and viral hepatitis and the largest opioid agonist treatment programme in Eastern Europe. For instance, 89.1% of Ukranian refugees who entered care in Poland initiated anti-retroviral treatment in Ukraine, 10.9% were diagnosed in Poland (underreported) and almost 10% reported previous tuberculosis infection.

Besides refugees from Ukraine, there are refugees and migrants from other parts of the world. In Poland for instance, besides migrants from Ukraine, hepatitis infection represents a major issue for refugees coming from Syria and Turkey. Access to HCV treatment is only offered within the national framework and vaccination for Hep B is infrequent.

Challenges

- **Health system capacity:** health systems must be able adapt to maintain treatment for displaced persons. For instance, Poland alone has seen a 20% increase in people, most of them women, needing HIV care. This is also a challenge for harm reduction, gynaecological and mental health services.
- **Transit and continuity of care**: Many people are in transit to other countries, creating challenges for health system documentation, service provision, continuity of service and treatment adherence.
- **Availability of and access to regimen used in Ukraine in EU countries**: Most refugees with **HIV** were receiving TLD (tenofovir, lamivudine, and dolutegravir), a generic fixed-dose combination pill, in Ukraine. TLD is not licensed in the EU. National authorities were able to use articles 5(1) and 5(2) of Directive 2001/83/EC as a basis for the supply of non-authorised products for refugees from Ukraine, which enabled a short-term donation of TLD generics to Poland. It was only available for a brief period but helped patients changed to a two-pill tenofovir/emtricitabine plus dolutegravir regimen more easily. Moreover, there has been challenges in accessing the oral **TB drugs**. There have been difficulties for doctors in providing displaced populations with **Opioid Agonist Therapy** and the same forms as in Ukraine.
- **Testing for timely diagnosis and linkage to care for HIV/HCV/HBV/TB/STI and vaccination for HBV, COVID-19, MMR:** as important as it is, testing might not be a priority for refugees facing several more immediate challenges.
- **NGO limited resources:** for expanding testing, harm reduction services as well as providing social, psychological, and legal support to refugees.
- **Language barrier and lack of information.**

Good practices and recommendations

- **Cross-sectoral and cross-country platforms** to share information, coordinate actions and facilitate contacts between NGOs, clinical societies, health authorities, and agencies. NGOs in Ukraine and in the EU and neighbouring countries collaborated in creating unique information online, offline centres providing information about HIV, TB, Viral Hepatitis, OAT services for refugees. These resources helped refugees to be linked to services in the host or transit countries.
- **Integrated approaches and services** to respond to the needs of diverse and changing population flows in a culturally sensitive manner.
- **Training of health and social workers** to meet the needs of key populations such as refugees of war and violence, or sexual violence survivors.
- **Hiring Ukrainian speaking peer navigators** to better reach out to communities.
- **Testing (and other prevention tools)** at **gynaecologist** or **general practitioner** level to increase reach, considering that most refugees from Ukraine are women and children.
- **Expanding community-based testing provision and HIV self-testing** programmes to support increased and targeted testing and reduce risk of late diagnosis.
- **Expanding harm reduction services and outreach** for refugees from Ukraine and other countries.
- **Emergency support** should include access to medical care, housing, social care, and employment.
- Low threshold to **access to opioid agonist therapy (OAT)** or other treatment and services for drug use disorders in line with the European Council directive.
- **Increase access to TB treatment** by reinforcing of national programmes, enable access to **inexpensive Dolutegravir based regimens** to maintain quality of care for refugees from Ukraine as this is the base of the main treatment in Ukraine.

3. The importance of tackling stigma

3.1. HIV-related Stigma and discrimination

Challenges

The **ECDC** recently presented their first community **survey of stigma** among people with HIV (the full report is here), the headline findings of the survey are:

- 28% of respondents felt ashamed of having HIV and 58% found it difficult to disclose their HIV status to others.
- People who experienced high levels of stigma were also considerably more likely to suffer from poor physical health and life satisfaction.
- While some people last felt they had experienced stigma some years ago, when the fear of HIV might have been assumed to be worse, just as many had experienced it in the last year.

Stigma in healthcare settings based on the survey was both more common, and more likely to be recent, than stigma experienced as coming from friends, family, or employers. Furthermore:

- 56% of participants expressed concern about being treated differently by healthcare professionals and 26% of respondents reported feeling this way within the past year.
- One in three individuals reported to avoid healthcare services due to fear of being treated differently. The recency of these experiences indicates that avoidance of healthcare services is more prevalent now than it was ten years ago.

As long as stigma and discrimination exist in society, both global and local initiatives will continue to fail to meet the objectives of reducing new infections, increasing access to voluntary counselling and testing, improving linkages to care, and increasing the number of people living with HIV with supressed viral load.

Good practices and recommendations

- **Ensure sufficient education and training of healthcare workers** in to increase knowledge and understanding of the HIV infection.
- **Ensure enforcement of anti-discrimination legislation**.
- **Increase people living with HIV's awareness of their rights**, as well as available remedies if their rights are violated.

3.2. Stigma and discrimination of key populations

Challenges

- There has been major scientific advances prevention and treatment, yet stigma and discrimination continue to hinder social progress and towards achieving SDGs (Sustainable Development Goals) and European HIV targets.
- Migrant communities, people who use drugs, sex workers, and transgender people often face additional barriers to accessing combination prevention, treatment and care due to stigma and discrimination.
- Certain situations such as homelessness, drug use or sex work increase vulnerabilities to HIV, TB, and viral hepatitis. The criminalisation, discrimination and stigmatisation of people and their behaviour further pushes them to the margins where risk taking might be higher and access to prevention, treatment and care limited.
- Discrimination and stigma against people living with HIV, migrants, people who use drugs, or people experiencing homelessness, sex workers, LGBTIQ+ communities is still common in all countries.

Good Practices and recommendations

- **Recognising that individuals are much more than their circumstances** promotes inclusivity and breaks down the barriers that often prevent individuals from accessing essential services, support, and opportunities. The language we use can either perpetuate or challenge

stigmatising attitudes. Therefore, it is crucial to use language that separates the disease, circumstances, or condition from the individual, as they do not define who they are as people.

- **Recognise that key populations are "not hard to reach"** and that it is the health system that difficult for some to access.

3.3. Stigma and discrimination faced by People who use drugs

Challenges

- **Repressive drug policies and criminalisation of drug use or possession** lead to discrimination against people who use drugs, who are often denied access to services and treatment.
- **Discriminatory media coverage** and rhetoric often perpetuates stigma against people who use drugs.
- **Fear of being denied access to services or opportunities in the hosting countries**, leads refugees from Ukraine living with HIV, who use drugs and on substitution therapy to avoid disclosing their status. This impact access their access to health services negatively.

Good Practices and recommendations

- **Training for law enforcement, media, and medical professionals** can help to increase their awareness, recognise habitual discriminatory attitudes and rhetoric, and eventually work towards their elimination.
- **Support and enable gender-sensitive peer-led harm reduction service provision**.
- **Provide support for organisations and countries that assist refugees** during the war in Ukraine.

3.4. Stigma and discrimination faced by LGBTQI+

Challenges

- **Higher risks of violence, poverty, and limited access to healthcare and employment** are faced by LGBTQI+ people who experience intersectional stigma and discrimination.
- **Discrimination from medical professionals**, including misgendering and ignoring the needs and voices of their patients, further exacerbates existing challenges.

Good Practices and recommendations

- **Prioritising the needs of marginalised groups** within the LGBTQI+ community and training medical professionals to better understand their unique needs.
- **Incorporating intersectionality in research** to help identify how different forms of stigma and discrimination intersect and impact the quality of life of LGBTQI+ people living with HIV.

3.5. Stigma and discrimination faced by Migrants

Challenges

- **Intersecting disadvantages including language barriers, poor health-seeking behaviours, socio-economic factors, and racial injustice** exacerbate challenges faced by migrants across Europe. They experience "health apartheid" based on race, faith, language, and geographical area, which leads to unconscious bias and disparities in service access.
- **Lack of quality data on migrant populations** prevents understanding the intersectional issues they face.

Good Practices and recommendations

- **Co-develop services with migrant communities** enables service providers to better understand and address their needs.
- **Meaningful engagement of migrants at all levels** of service planning and implementation can help ensure that their voices are heard, and their experiences are considered.
- **Community-led services** that are culturally competent and sensitive to the backgrounds and experiences of migrants are effective in addressing stigma and discrimination.

3.6. Criminalisation of People Living with HIV

Challenges

- **HIV-specific criminal laws** or general criminal laws applied to HIV (such as ones against assault, endangerment or even homicide) were in place in 129 globally.
- **Laws and prosecutions operating on outdated scientific knowledge** overreact to negligible risks if HIV transmission.
- **Laws used against marginalised members of communities**, including women, ethnic minorities, and LGBT people – perpetuate HIV stigma.

Good Practices and recommendations

- **Repealing or reforming laws that have been used against people living with HIV.** This has recently been done in Denmark, Montenegro, the Netherlands, Norway, Switzerland, Sweden and Zimbabwe.
- **Dissemination of combination prevention guidelines.** For instance, the UK has developed a U=U guidance, and is paralleled by similar initiatives by the Canadian government and the US' Center for Disease Control. The ECDC or a similar competent body could issue similar **pan-European guidance**. Policymakers and NGOs could work with European parliamentarians to educate them about the harms of a punitive approach to HIV.

3.6. Stigma, discrimination, and criminalisation faced by Sex Workers

Challenges

- **Criminalisation of any part of sex** work leads to negative impacts on the health and wellbeing of sex workers and prevents them from accessing the help they need. In criminalised environments, sex workers are more likely to experience sexual or physical violence, which puts them at higher risk of contracting HIV and other sexually transmitted infections (STIs).
- **Stigma and discrimination** undermine access to healthcare and support services.
- **Limited access to healthcare services** further exacerbates these risks, as sex workers may be reluctant to seek medical attention due to fear of arrest or discrimination.

Good Practices and recommendations

- **Ending the criminalisation of sex work** is an important first step in tackling health and social disparities faced by sex workers.
- **Extensive community-based sexual health services** can foster stigma free testing environments and empower sex workers.
- **Adopting a human rights-based framework**, rather than a moralistic approach, is key to acknowledging and respecting the dignity of sex workers.

3.7. Working in partnership to achieve zero discrimination

To effectively address stigma and discrimination, it is important to take a comprehensive approach that involves multiple stakeholders and collaboration.

- **Government support to NGOs and community-based organisations beyond just funding** their activities would allow them to decide how best to provide accessible services to prevent diseases and support people in need to get treatment and care.
- **Collaborative data collection with NGOs and community-based organisations** can help ensure that the voices and experiences of key populations are heard.
- **Policy harmonisation between different branches and ministries** (e.g. between justice and health) is necessary to end stigma and discrimination at every level. There is a good example of the Global Partnership for Action (GPA) which is a collaboration between UN agencies, civil society organisations and governments to end HIV-related stigma and discrimination at every level.

Endorsing organisations

If your organisation would like to endorse this, we kindly ask you to complete our online form (here).