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

Joint Statement

Thematic Networks led by EU Civil Society Forum on HIV/AIDS, Hep and TB

1. Background

1.1. Introduction

The EU Civil Society Forum on HIV/AIDS, tuberculosis (TB) and viral hepatitis (CSF) is a body composed of national and European community and civil society networks (please find full list here). It provides critical information from the field to European and International Health agencies. It supports joint actions and networking between its members. It aims to advance policies and interventions that improve the health and well-being of communities that are most affected by HIV, viral hepatitis, and TB.

With the European Health Policy Platform Thematic Network on HIV/TB/VH/STIs, the CSF held two webinars. One looked at the issues and good practices in addressing **Standards of Care: HIV, VH, and TB – Good Practices and Ensuring Prevention & Care for People on the move**; the other focused on **Eliminating Stigma, Discrimination and Criminalisation of Key Populations**. The aim of this Joint Statement is to draw attention to certain gaps perceived by the HIV, TB and viral hepatitis communities that need to be tackled. It highlights good practices and recommendations that national authorities, health care providers, community and civil society organisations, legislators, EU institutions and

private sector could help transfer, adapt and scale up to support the European Commission to draw attention to key issues faced by concerned community. The challenges and good practices underscored do not aim to represent a comprehensive and exhaustive list.

1.2. The HIV, TB and Viral hepatitis health gaps

The Global AIDS Strategy 2021–2026 and the World Health Organization call for renewed focus on viral hepatitis, HIV and TB epidemics within the European Region. They highlight the needed focus on reducing inequalities that drive the HIV/AIDS epidemic and ensuring that people who are not yet accessing HIV services do access these. Countries committed to providing better services; multi-disease care and diagnostics; reaching out to key populations; engaging communities; re-focusing of testing; treatment scale-up and rebound prevention by using a diversity of platforms.

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 on HIV and viral hepatitis draws attention to the region's being off track to meet the 2030 95/95/95 target for HIV. By 2020, only 60% of people with HIV knew their and were virally suppressed (last 95). The biggest shortfall in the target's individual steps was testing, with 77% diagnosed.

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 have committed to work towards the 2030 Sustainable Development Goals. The European Commission has since the start emphasised its support to help member states achieve them. While countries are responsible for their health system, the EU has several policies, financial and technical support tools complementing member states action and supporting cooperation across countries.

2. Improving healthcare, including cross-border

2.1. Improving standards of care and their delivery

There is great variation in access to and in the quality of care delivered across clinics in Europe that needs to be addressed. Governments, health care providers and community-based organisations need to update their prevention and approaches considering evolving needs of populations at risk, patients, and current financial limitations.

Challenges

- **Changing clinical demands and care:** an ageing population of people living with HIV, retiring first generation of HIV nurses and physicians, need for broader education with increased migration refugee flow with various needs, new treatment strategies based on long-acting regimens.
- **Unavailability of TB Medicines:** TB represents a small market in the EU/EEA/UK for pharmaceutical companies. They are reluctant to incur the costs of registration of new drugs in the EU, UK. 1) Child formulations of the regular TB drugs – available elsewhere in the World for the past 10 years; 2) Rifapentine, important for treating latent TB and a component in the first WHO-approved 4-month regimen, a 2-month reduction on the current length of treatment for drug-sensitive (i.e. regular) TB.
- **Expanding PrEP access:** oral PrEP is still unequally available across Europe to those who would benefit and there is a risk that long. **Access to long-acting HIV medicines** for prevention and treatment
- **Lack of prioritisation of viral hepatitis** resulting in lack of access to adequate screening and HCV treatment.
- **Under and insecure funding basis of civil society and community organisations:** these are a key resource in providing 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 situations such as those created by the war in Ukraine and in other parts the world.
- Under-use of **peer- navigators programmes** in services.
- **Barriers to decentralised testing:** To enhance the uptake and diagnosis of HIV and STIs, WHO recommends the integration of additional approaches to testing such as decentralised and

demedicalised service delivery, peer-led programmes, self-sampling collection, and the use of digital platform. However, scale up is hindered by the 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** leaving 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). A vital part of auditing is the re-audit, which evaluates whether conducting an audit has resulted in an improvement in services. 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 also between individual clinics. The re-audit two years later found improvements in many areas.
- **Participatory approaches to defining standards of care and prevention**: The European Clinical AIDS Society (EACS) and the European Centre on Disease Prevention and Control (ECDC) are collaborating with healthcare professionals and clinicians from across Europe, as well as with communities of people living with or affected by HIV, TB, viral hepatitis, STIs and partners, to define standards of care (including prevention) and an audit tool which can be used in the various participating countries.
- **Standardised Package of Care in TB to be provided by civil society:** TB Europe Coalition (TBEC), PAS and WHO, with the support of the Global Fund TB-REP2 programme, developed a Standardised Package of services. It provides a framework for public payers to contract CSOs for defined services. It 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.
- **Decentralised and outreach testing**: community-based organisations and civil society 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 (e.g. rapid testing, self-testing, self-sampling, screening Hand-held X-ray equipment, enhanced by AI).
- Interprofessional collaboration among health professionals (e.g., general practitioners, sexual health specialists, community health workers, mobile nurses and inclusion of general practitioners, etc.) to improve **decentralised implementation** and rollout of current and future **biomedical interventions** to populations who can benefit most is needed. Yet an effort to scale up access to HIV biomedical interventions should not overshadow ierventions for critical HIV vulnerability factors, including harm reduction programmes in the area drugs use, anti-

discrimination, decriminalisation, social protection and housing. Moving forward, a holistic approach is critical.

- **Digital platforms** as complementary tools: For instance, *OneImpact* is used by TB services in several countries and is especially effective in Ukraine. Despite the war and Russian invasion, 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. This digital platform is a promising tool that could be effective in other settings.
- **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**: prevalence of hepatitis C (HCV) has been reduced, not only among people with HIV, but among the general public thanks to a national, universal testing and treatment programme. This includes a door-to-door screening programme. Moreover, hepatitis C treatment has been delegated to a national network of 96 local primary care clinics. So far, two-thirds of the country's population of 3.7 million has been screened for hepatitis C antibodies. Of these 98,725 were RNA-positive, i.e. had active chronic hepatitis C. Of those, 75,045 (76%) have initiated at least one round of antiviral treatment and 99% of them are considered to be cured. The percentage of screening tests that were positive for hepatitis C RNA declined from 5.4% in 2015 to 1.8% in 2022. Georgia plans a similar national screening and vaccination project for HBV.
- **HCV programme in prison in Luxemburg:** The programme is funded by the Ministry of Justice and aims to provide healthcare to people in prison, including testing, treatment, and vaccination against hepatitis A and B. The nurses also provide counselling and follow-up appointments for released people and work with wardens to prevent the transmission of diseases in prison through condom availability and needle exchange programmes.

2.3. Cross-border care - displaced persons, refugees, migrants in precarious situations

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. It is critical to ensure continuity of care for people displaced by the war including access to testing, prevention, treatment, and care. Most of the people who came to Poland (and neighbouring countries) from Ukraine since the invasion of Ukraine are women. According to data from Poland about patients from Ukraine who entered care, 89.1% initiated anti-retroviral treatment in Ukraine, 10.9% were diagnosed in Poland (underreported) and almost 10% reported previous tuberculosis infection. Over half of new HIV diagnoses in the European region are diagnosed late and present increased numbers of multidrug resistant TB. They remain undiagnosed in all Central European populations.

Besides refugees from Ukraine, there are refugees and migrants from other parts of the world. In Poland for instance, besides migrants from Ukraine and Eastern Europe, hepatitis infection represents a major issue for refugees coming from Syria and Turkey. A considerable proportion are people co-infected with hepatitis. Access to HCV treatment is only offered within the national framework and vaccination for Hep B is infrequent, with small numbers of migrant populations being vaccinated across Europe.

Challenges

- **Health system capacity**: health systems must be able adapt to maintain treatment for displaced persons. For instance, in Poland, 3000 persons from Ukraine have entered the system of HIV care. this is also a challenge for harm reduction programme capacity. Moreover, people present additional needs, for instance gynaecological or for mental health issues.
- **Transit and continuity of care**: Many patients being in transit to other countries has created challenges for service providers and patients for compliance and treatment continuation.
- **Availability of and access to regimen used in Ukraine in EU countries**: Most refugees with HIV were receiving Tenofovir, Lamivudine, and Dolutegravir (TLD) in Ukraine. Yet, TLD is limited in use the EU/EEA due to price and patent which does not allow generics use in the EU in contrast to Ukraine. In the context of the humanitarian crisis because of the Russian aggression on Ukraine, because of the strong recommendation not to switch treatment and the limited supply for TLD based regimen in EU/EEA countries, national authorities were advised to use Directive 2001/83/EC. Articles 5(1) and 5(2) of the directive 2001/83/EC as a basis for the supply of non-authorized products for refugees from Ukraine (e.g. generic TLD). This enabled a donation of TLD generics to Poland. However, it was available only for a brief period as there is a major issue with licensing in the EU. 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 for providing social, psychological, and legal support to refugees.
- The transit of many patients to other countries has created challenges for both service providers and patients in terms of compliance and treatment continuation.
- **The consequences of stigma or fear of stigma**: may have prevented some people living with HIV, TB, HCV or using drugs to disclose health needs at registration or presenting at HIV, viral hepatitis or TB prevention/treatment services.
- **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. Moreover, 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. It helped to organisations to refer and link refugees to the needed services in the host or transit country(ies).
- **Integrated approaches and services** to respond to the needs of diverse and changing population flows in a culturally sensitive manner.
- **Training to health and social workers** (for example, on how to approach mental health issues, sexual violence)
- **Hiring Ukrainian speaking peers** to better reach out to communities.
- **Testing (and other prevention tools)** should be offered at **gynaecologist** or **general practitioner** level considering that most refugees from Ukraine are women and children. **Expanding community-based testing provision and HIV self-testing** programmes would 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** is needed 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…

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, indicating a substantial increase compared to a decade ago.
- One in three individuals reported to avoid healthcare services due to the expectation 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.

If 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, having better 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
- Make people living with HIV aware their rights and available remedies if their rights are violated.

3.1. Stigma and discrimination of key populations

Challenges

- Despite scientific advances in improving prevention and treatment, social progress has lagged behind. Stigma and discrimination pose challenges in achieving SDGs 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, or behaviours in people's lives like homelessness, using drugs or engaging in sex work increase vulnerabilities to HIV, TB and viral hepatitis among other things. People and their behaviour are stigmatised, discriminated and criminalised. It thus pushes people 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

- It is important to recognise that these individuals are much more than their circumstances, diagnoses, or conditions.
- 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 maybe the health system that difficult for some to access.
- By recognising the person behind the circumstances, we can promote inclusivity and break down the barriers that often prevent individuals from accessing essential services, support, and opportunities.

3.2. 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.
- The war in Ukraine exacerbates the situation for people who use drugs who become refugees in European Union member states because they tend to hide their drug use, HIV status, or that they were on the substitution therapy back home to avoid being denied access to services or opportunities in the hosting countries.

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 enabling of peer-led harm reduction service provision, which are gender sensitive
- It is important to provide support for organisations and countries that assist refugees during the war in Ukraine.

3.3. Stigma and discrimination faced by LGBTQI+

Challenges

- LGBTQI+ experience intersectional stigma and discrimination, with higher risks of violence, poverty, and limited access to healthcare and employment.
- 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 can also help to identify how different forms of stigma and discrimination intersect and impact the quality of life for LGBTQI+ people living with HIV.

3.4. Stigma and discrimination faced by migrants

Challenges

- Migrants across Europe face multiple disadvantages, including language barriers, poor health-seeking behaviours, socio-economic factors, and racial injustice.
- They also experience "health apartheid" based on race, faith, language, and geographical area, which leads to unconscious bias and disparities in service access.
- The lack of quality data on migrant populations prevents understanding the complexities and intersectionalities they face.

Good Practices and recommendations

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

3.5. Criminalisation

Challenges

- Globally 129 countries in the world had either HIV-specific criminal laws or have applied general criminal laws (such as ones against assault, endangerment or even homicide) to people with HIV in the past decade.
- Laws and prosecutions often overreact to negligible risks if HIV transmission and may operate based on very outdated scientific knowledge.
- The laws tend to be used against the more marginalised members of communities – such as women, ethnic minorities, and LGBT people – and themselves perpetuate HIV stigma.

Good Practices and recommendations

- Denmark, Montenegro, the Netherlands, Norway, Switzerland, and Sweden repealed or reformed laws that have been used against HIV.

- The Netherlands limited their anti-HIV law and Denmark suspended theirs based on the scientific evidence, as have several US states, Victoria state in Australia, and, importantly, Zimbabwe in Africa, which had previously conducted several high-profile prosecutions.
- In the UK nations, guidance on subjects such as 'U=U' and what viral phylogenetics can and cannot show have been developed. Similar guidance and directives to prosecutors have been issued in Canada, and in the US by the US Centers for Disease control.
- Following this example, the ECDC or a similar competent body could issue similar pan-European guidance, policymakers could work with EU parliamentarians, and policy-developing NGOs could work with European parliamentarians or policymakers to educate them about the harms of a punitive approach to HIV and other communicable diseases.

3.6. Stigma, discrimination, and criminalisation faced by sex workers

Challenges

- Criminalisation of any part of sex work including the criminalisation of the purchase of sexual services leads to negative impacts on the health and wellbeing of sex workers.
- Stigma and discrimination undermine access to healthcare and support services.
- 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 (STIs).
- 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 and deportation for undocumented migrants.
- If any part of sex work is criminalised, we will not reach the targets and sex workers will not get the help they need.

Good Practices and recommendations

- Eliminating the criminalisation of sex work including the criminalisation of clients and non-exploitative third parties is an important first step in tackling health and social disparities faced by sex workers. Adopting a human rights-based framework, rather than a moralistic approach, is key to respecting the dignity of sex workers.
- It is crucial to offer extensive community-based and community-led sexual health services.
- Sex workers should be meaningfully included in the development, delivery, and evaluation of health services. Supporting peer-led health service provision is key to reach the most marginalised 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 collaboration with multiple stakeholders.

- Governments should provide support for NGOs and community-based organisations beyond just funding their activities, allowing 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 included in efforts to address stigma and discrimination.
- 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. The GPA mechanism is a way of achieving harmony of policy between different arms of the state.

To endorse the statement

If your organisation would like to endorse this, we kindly ask you to send your organisations' logo to chiara.longhi@eatg.org.