



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

## CSF meeting summary 2 September, 10:00-12:30 CEST

### Contents

1. Coordination team report	1
1.1 EU4Health work programme	1
1.2 Global Fund	2
1.3 Evaluation Survey	2
2. Improving mental health and well-being of people living with or affected by HIV, TB and viral hepatitis	2
2.1 New Psychoactive Substance (NPS) use and mental health: possible harm reduction responses to the emerging challenges	2
2.2 EATG HIV and mental health research	2
2.3 ICRSE's project support to LGBTIQ sex workers' mental health	3
2.4 HIV treatment and well-being. The Nordic Treatment Quality Survey (HIV-Nordic)	4
2.5 TB Alert's TB psychosocial counselling training materials	5
2.6 Discussion	5
2.6.1 Presenter additional comments and recommendations	5
2.6.2 Comments from meeting participants	5
3. ECDC stigma survey and Dublin reporting	6
4. AOB	6
4.1 Presidency for Czech Republic coming (July – Dec 2022)	6
4.2 Next CSF meeting	7

## 1. Coordination team report

### 1.1. EU4Health work programme

**Roberto Perez Gayo, Correlation-EHRN**

PPT available [here](#)

Calls expected mid-October 2021

- 1) Scaling up and strengthening good practices of community-based services to enhance the effective prevention, testing and linkage to care among risk groups for HIV/AIDS, tuberculosis, viral hepatitis and sexually-transmitted infections. They will also pursue harm reduction and peer support programmes. (5 million €). Civil society organisations (associations, foundations, NGOs and similar entities).

- 2) Reduce liver and gastric cancer caused by infections (2 million €): Academia and education establishments, research institutes, hospitals; enterprises in the field of public health; Member States' authorities and established networks in the field of public health.
- 3) Civil Society operating grants not foreseen. In the last period, there has been a series of advocacy activities by European NGO health networks to restore them and to improve meaningful consultation with Civil Society. After some resistance, EC agreed to look at possible solutions for September.

## 1.2 Global Fund

**Ganna Dobakh, EHRA**

During the summer, the Global Fund had an urgent meeting on GF strategic framework. Consultations will be finalised by November. Consultations have just started, but no sign of open calls at this time. Once a draft has been received from the national delegation, EHRA will share with CSF for comments/contributions. Note: GF is not opening for comments from CS, they are basing this off of previous participation in GF regional forums.

## 1.3 Evaluation Survey

**Ferenc Bagyinszky, AAE**

The Coordination Team finalised the 1-year evaluation survey of CSF. Members can expect evaluation survey invitation in the coming weeks.

# 2. Improving mental health and well-being of people living with or affected by HIV, TB and viral hepatitis

## 2.1 New Psychoactive Substance (NPS) use and mental health: possible harm reduction responses to the emerging challenges

**Ganna Dobakh, EHRA**

PPT available [here](#)

This project began two years ago, having now completed eight studies, primarily in Eastern Europe. Findings indicate that the rapid spread and growth of interest in NPS is associated with: low price, accessible, purchased through the darknet, repressive drug policies (undefined legal status for NPS), and free movement of commercial goods/products. The health systems are not ready to address the problem of people using NPS. Especially during COVID, drugs became more spread out.

Key risks/consequences related to NPS use include: overdoses, increase in number of unprotected sexual contacts; mental health (paranoia, hallucinations, panic attacks, psychosis, schizophrenia, suicidal thoughts, aggressiveness); and more.

Main challenges: disconnection between harm reduction and mental health services, no naloxone, and NPS users not accessing harm reduction settings in person because this is mostly taking place online. Mention made to [NEPTUNE Project on clinical practice and NPS harms](#).

- Recommendations: need more data on NPS use, and more resources to connect mental health & harm reduction.

Read the eight country reports [here](#). Join EHRA for a series of regional discussions with activists, doctors on the report findings. The first event will take place on 14<sup>th</sup> September.

## 2.2 EATG HIV and mental health research

**Daniel Simões, EATG Consultant**

PPT available [here](#)

EATG has undertaken an exploratory, cross-sectional survey targeting two groups: people living with HIV and persons working in HIV organizations at the local, regional, or international level in the WHO European Region.

The survey was focused on people living HIV, however a limited representation of diverse demographics. Responding people living HIV were mostly: cisgender, self-identified as heterosexual, living in capital cities, between the ages of 30-49 years, completed high school level or higher education, were employed, and were homeowners.

Key findings from the responses of people working in HIV organisations: –many mental health (MH) issues are reported, including depression, anxiety, isolation, shame, self-blame, suicidal feelings, etc.

The most reported mental health services provided, include peer support, psychological support, help groups. Many report that psychological support, therapy sessions and referral systems are widely missing in terms of availability for PLHIV. 50%+ of the PLHIV sample indicated that MH issues increased during COVID

Key findings from the responses of people living with HIV:

- Increase of mental health issues post-diagnosis observed
- Over half indicated that they have never had a MH examination, nor ever visited a MH specialist
- Majority (24%) of non-EU/EEA respondents accessed a peer support worker
- A small proportion of respondents have ever received MH treatment
- Over 50% of the sample reported 3+ symptoms that would indicate need for a proper assessment for depression
- Majority of people living with HIV resort to family and friends for support
- Noted declined access to treatment pre and post COVID-19
- Awareness of services: concerning discrepancy between people living with HIV and HIV organization reporting of MH services provided
- Over 50% reported that HIV stigma had an impact on self-worth, ability to engage in relationships and sex life, etc.

Overall recommendations:

1. Raise awareness regarding mental health issues among people living with / affected by HIV, particularly those from marginalised or criminalised populations.
2. Foster and improve coordination between mental health services/responses and other HIV services.
3. Ensure referral from HIV care services to mental health support services where mental health support services in HIV care is not possible.
4. Enhance dialogue between HIV specialists and mental health specialists to increase knowledge of existing needs, services and links from both sides.
5. Mental health care response should entail options responding to different levels of demand and as well as empowerment of patients in self-management of their mental health issues, when possible.
6. Policies and guidelines should be updated to reflect diverse needs, including possibilities for de-medicalized services.
7. Need to differentiate cases where support requires pharmacological interventions and those where it does not.
8. Support research to generate evidence, define programmatic requirements and formally acknowledge trained peer work in the field of mental health.

See more in the [full survey report](#) and [short survey report](#). CSF members have early access to the briefing paper but **please do not share** this as it is embargoed.

### 2.3 ICRSE's project support to LGBTIQ sex workers' mental health

Jules James, ICRSE

PPT available [here](#)

The project looked at the link between sex work and MH, as this is often left out of the discussion because this has traditionally been used as an anti-sex work argument to justify an association between sex work and mental illness.

One part of the project involved the organising of thematic sessions: anxiety, sexual violence, addictive and compulsive behaviours, suicide, body image. Sessions were delivered by certified therapist. In parallel was a support group for LGBTQI sex workers' and rights activists. It was a closed group where SWs could exchange with peers while receiving support from therapists.

A briefing paper and toolkit for sex workers' rights activists were developed after consultations on factors impacting the mental health of sex workers; access to mental healthcare for sex workers; and best practices within the community. The briefing paper examines:

1. Factors impacting MH of sex workers (criminalisation and migration, violence from police/clients/society, LGBTQI SWs experiencing intersectional stigma, legal consequences such as risk of losing housing/child custody)
2. Access to MH services for sex workers (lack of knowledge of services and experiences of stigma as barriers)
3. Coping strategies and sex worker-led initiatives

The briefing paper includes recommendations.

The toolkit for sex workers' rights activists addresses the definition of mental health (and a mental health crisis); what to do; recommendations of what organisations can do to improve the MH of sex workers; other resources.

Invitation shared for 11am (CET) on 6<sup>th</sup> October joint launch event with National Ugly Mugs (UK). Presentation of [research from PG Maciotti](#), ICRSE briefing paper + toolkit, other sex worker-led initiatives.

## 2.4 HIV treatment and well-being. The Nordic Treatment Quality Survey (HIV-Nordic)

**Sini Pasanen, Positiiviset**

PPT available [here](#)

HIV-Nordic is the co-operative body of the Nordic organizations for people living with HIV, including Hiv-Denmark, HivNorway, HivFinland, HIV-Sweden and Hiv-Iceland.

While individuals in Nordic countries are privileged to get treatment and care from some of the best health systems in the world, many PLHIV are not open about their HIV-status to anyone other than HIV-doctor and nurse. This means that many people are dependent on the information provided by healthcare professionals.

Observed changes in treatment and care in the past 2-3 years, such as: shortened time at clinical visits; reduced involvement in care/treatment; not understanding why treatment (medication) has changed. Patient participation is important for the treatment adherence, as well as for quality of life. Elements related to mental health and mental well being: Perceived self-efficacy, competence, subjective well-being. Funding was provided by the Nordic Welfare Center.

Aims of this project and the survey:

- Collect information about HIV-treatment and care received during the past 2-3 years in the Nordic countries.
- Have people experienced any changes?
- Data for our advocacy work
- Gather information on the needs for more support, training, treatment literacy, etc.

### Main findings

64% of respondents are satisfied with their patient-doctor relationship and find it easy and functional. There are no remarkable changes when comparing today and 2-3 years ago.

80% trust the confidentiality; 66% think that their privacy is well taken into account; and 55% feel involved in their own HIV medication, treatment and care.

54% strongly agree that they understand what the HIV doctor tells them about HIV medication and treatment.

Before a HIV doctor's appointment, 18% are worried if their HIV medication is still effective, versus 47% who strongly disagree with having such worries.

20-25 % weren't sure if they have side effects from their current HIV medication.

12% of the respondents felt that they didn't have a choice when it comes to changing medication.

Read the full report [here](#). Nordic Meetup on living with HIV to take place on 4 September to discuss results, gain insights, and discuss living with HIV during COVID-19.

## 2.5 TB Alert's TB psychosocial counselling training materials

**Sameer Sah, TB Alert**

PPT available [here](#)

MDR (multidrug resistant) TB requires a long and high-burden treatment that impacts one's overall health, quality of life, finances, etc.

According to the WHO's 2020 Global TB report, treatment success rate for MDR/XDR (extensively drug resistant) TB was only 57%.

During visits in Malawi, the TB training and orientation at that time focused on treatment administration options; treatment adherence counselling; and referrals for further diagnostic tests and adverse drug reactions. However, it lacked provision of psychosocial support. This resulted in TB Alert's recently published manual, [Psychosocial Counselling and Treatment Adherence Support for People Living with Tuberculosis](#). Content includes:

- Stepped psychosocial support pyramid model
- Comprehensive approach that includes gender, stress, stigma and discrimination as barriers to diagnosis and treatment
- Specific challenges for key populations (ie. Miners and prisoners)
- Advances in digital health technologies providing opportunities to improve TB care
- Multidisciplinary collaboration highlighting importance of CSOs
- Concept of guided conversations
- Community-led monitoring
- Psychosocial support needs of people with complex comorbidities

Next steps:

- Ensure that psychosocial support is a part of national TB strategies/ bilateral and multilateral donors
- Develop the manual into a participatory training programme and train health and care workers
- Translate the manual in other languages and publish copies for extending reach
- Conduct research to understand better how PSS can improve treatment outcomes for people with TB

## 2.6 Discussion

**Roberto Perez Gayo, Correlation-EHRN**

### 2.6.1 Presenter additional comments and recommendations

Acknowledging the impact on mental health of structural factors, such as stigma, discrimination, criminalization and violence. There is a need to continue advocating that sex work is work and the decriminalisation of sex work is crucial as this impacts stigma and mental health. In general, involve sex workers in research, policy making, consultations, and trainings for healthcare professionals. Lastly, fund sex worker-led organisations. Further, there is a need to raise awareness of the stigmatizing and hurtful consequences of conflating drug use and mental health. Drug use and drug dependency is not a mental health condition.

The importance of community-based research (CBR) was raised, and the need to have resources for communities to carry-out their own research. The intersecting experiences of stigma and discrimination must be considered when discussing mental health recommendations. Mention of epi-data lacking indicators for how many people (living with HIV/Hepatitis/TB) have received mental health counselling.

There is a need to raise awareness on the relevance of mental health and having services available, and to examine the models currently in place. In many countries, professional mental health support is difficult to access due to high

demand and high cost. Stepped models could be an interesting approach to explore going forward, as well as the creation of referral networks. LMICs require particular attention as from the presentations today, it appears that there is a lack of mental health specialists in these countries. Finally, mental health training and awareness must take into account the structural issues of intersectional stigmatisation that takes place in healthcare settings but also more broadly in society.

## 2.6.2 Comments from meeting participants

The works shared today should be published in peer-reviewed journals that have high impact factors. This would reach the psychologists and other related experts. Documents are needed for EU funding, and this would be one avenue.

The issues related to the topics presented today vary widely from East to West – keep the subregional differences in mind. Any capacity building, partnerships and advocacy efforts must acknowledge the sub-regional language differences too / how this information is collected/communicated. There was also mention of a siloed approach to overall health and well-being. Health systems must be more inclusive of the social determinants for affected PLHIV.

Mention of NAT working on a publication addressing the role of health professionals in care pathways and frameworks. Projected publication date: October 2021.

The demand for intersectional approaches to overall health and well-being were raised again. Also, person-centred care must be pushed forward at national level. The new UNAIDS strategy focuses on the structural issues, but health systems don't reflect the guidelines.

There was also the expressed desire for more collaborative projects with different organisations to address intersectionality. This also allows for space for organisations to learn from one another, share information/best practices, and carry-out more in-depth population specific research.

## 3. ECDC stigma survey and Dublin reporting

### **Cheryl Gowar, National AIDS Trust consultant to ECDC**

Collaboration between AAE, EATG, and ECDC on a stigma and discrimination survey; intended to serve as a benchmark, to be repeated leading up to the 2030 UNAIDS targets. Covering the whole WHO European region.

Also asking for civil society input and contribution moving forward.

AAE and EATG collected a list of country focal points to support the survey translation and dissemination. Country focal points (CFPs) will have the opportunity to comment on the survey tool and report draft(s). Benefits to the CFPs include being acknowledged as authors in the report and report slide sets to be used in your own work. CFPs are also encouraged to express expectations related to project goals, benefits, and support needed. This can be discussed at CFP kick-off meeting, or can be addressed directly to Cheryl via email.

How survey findings will be used:

- Build into national monitoring to assess progress over time to SDGs
- Close a data gap by generating community-led/informed data to inform advocacy
- First step to have standardised European data, with the backing support of an international organisation
- To be repeated every other year or so Noted limitation that the survey will only be offered online, at least for the first survey round
- It will allow for comparison between what's said at ministry level vs what the community experiences

Tentative timeline:

1. Kick off meeting in September with focal points
2. Survey translation
3. Ethics finalised in September
4. Survey launch in October
5. Report draft in Jan/Feb 2022

CSF members are invited to collaborate as a CFP and/or share contacts to recommend. Contacts particularly needed in Monaco, San Marino, and Turkmenistan. Any questions can be directed to Cheryl ([Cheryl.gowar@NAT.org.uk](mailto:Cheryl.gowar@NAT.org.uk)).

## 4. AOB

Sini Pasanen, Positiiviset/AAE

### 4.1 Presidency for Czech Republic coming (July – Dec 2022)

Robert Hejzak

PPT available [here](#)

Projected priorities coming for the Czech Presidency:

1. Improving access to medicines in the EU (long-term EU pharmaceutical policy)
2. Oncology (prevention, diagnosis, treatment & quality of life)
3. Vaccination (trust in public health systems, fighting hoaxes)
4. Strengthening the role of the EU in the context of global health

Auxiliary topics: rare diseases, mental health (expert conference in October 2022), and topical issues.

Invitation to NGOs to organise official events “under the auspices of the Czech Presidency”. Robert Hejzak open to be the liaison point on this. This is relevant for increasing patient advocacy in this forum, and other topics can be included. See Robert’s PPT for more details.

Comments/discussion:

- Suggested to have working group to increase civil society engagement with Presidencies
- Good to have some kind of framework for HIV NGOs to have a stronger presence during Presidency events
- Concerns around ECDC where COVID-19 has taken front stage over HIV in the advisory forum, despite numbers for HIV/AIDS not significantly decreasing

### 4.2 Next CSF meeting

During the first week of November. Exact date 4 November 10:00-12:30 CET.

Possibility of F2F meetings in the future is dependent on funding. CSF members can inform the secretariat of any proposed items/topics for future agendas.

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Comment/links from chat:

Hi colleagues, you might be interested in this statement from the International Network of People who Use Drugs and Harm Reduction International on drug use and mental health: <https://www.hri.global/contents/2132>