

EUROPEAN COMMUNITY PERSPECTIVE  
ON STIGMA  
AS A CONTINUED BARRIER  
TO TESTING FOR HEP/HIV

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CIVIL SOCIETY FORUM



# European Community

- North, South, East, West, Central
- EU Countries, Non-EU, neighbouring countries, EECA, Candidate countries
- Key populations
- People who use drugs, sexworkers, LGBTQI, immigrants, transgender, people living with HIV/Hepatitis, prisoners, marginalised people, people in detention
- NGOs, networks and communities

EU HIV/aids,  
Viral Hepatitis  
and  
Tuberculosis  
Civil Society  
Forum

CSF is an informal advisory body established in 2005 by the European Commission to facilitate the participation of NGOs and networks, in European policy development and implementation as well as to exchange information.

Members of the CSF come from all over Europe and are selected by the Commission following a call for expression of interest.

# STIGMA

- A mark of disgrace associated with a particular circumstance, quality, or person.
- Synonyms: shame, disgrace, dishonor...
- Commonly understood as a process of devaluation.
- Stigma can have many outcomes, such as discrimination.
- In the context of HIV and Hepatitis, stigma can affect how and when someone accesses services, how people interact with each other, how someone perceives themselves and their self-esteem.
- Stigma leads to people not being treated with dignity and respect.

# HIV AND HEPATITIS RELATED STIGMA

- Ever since the first cases of AIDS in the early 1980s, people living with HIV have been stigmatised.
- Hep C is dangerous but treatable. HIV can still be a serious, life-threatening illness if undiagnosed.
- Most people don't know much about Hepatitis C, lot of ignorance
- In most European countries Hep C awareness rising came hand in hand with new treatment.
- Among people who inject drugs "*everyone has Hepatitis C*"
- What does it mean to a person to get a positive Hep/HIV test result?

# STIGMA INDEX

Estonia, Moldova, Poland, Turkey, and Ukraine implemented the People Living with HIV (PLHIV) Stigma Index in each of their countries 2010-2011.

To better understand the issues surrounding late diagnosis and delayed treatment, five new questions were made part of the roll-out of the PLHIV Stigma Index2 in these countries.

# STIGMA INDEX

Hesitation to test because of fears of social stigma.

Loss of spouse or partner, friends or family, ability to marry, fears that one's children would be stigmatised

Concerns about being associated with stereotyped groups, and concerns about losing one's employment or schooling.

Also specifically not feeling ready to deal with one's HIV infection, fears of mistreatment by healthcare workers, fears about violations of confidentiality, not knowing where to go for care, and a fear of being seen accessing care.

Criminalisation fears

COMMUNITY  
PERSPECTIVE  
ON STIGMA

Stigma, shame,  
HIV, Hepatitis –  
they are siblings,  
for sure.



COMMUNITY  
PERSPECTIVE  
ON STIGMA

Stigma, shame, HIV,  
Hepatitis – they are  
siblings.

Discrimination is easier  
to deal with than  
stigma.

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Internalized homophobia,  
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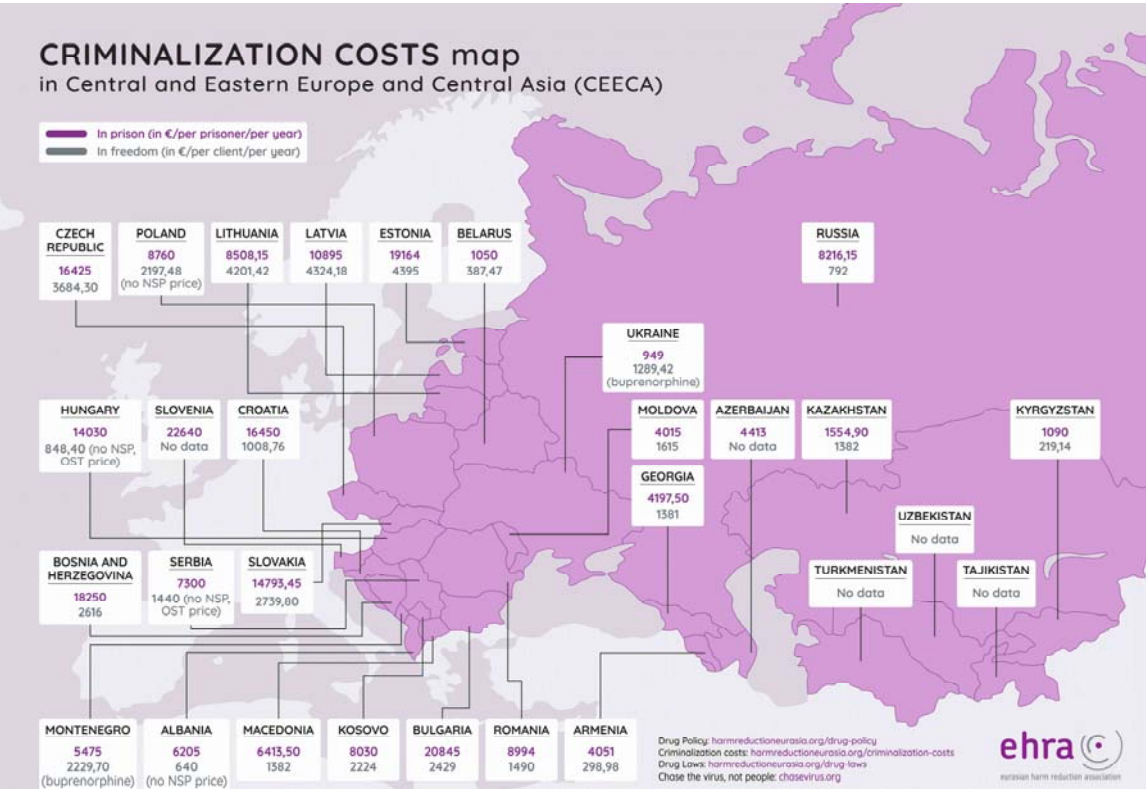
Social determinants, church, sex and sexuality



REDUCING HEP/HIV RELATED STIGMA

# DO ADVOCACY, PROMOTE THE RESULTS

“Criminalization costs” – simple assessment conducted by EHRA members to compare state spending on the criminalization of the drug possession versus support of person, who use drugs with social and health care services in freedom.



# HOW TO REDUCE STIGMA

- Legal protection to get healthcare, incl. testing, treatment and support.
- We have to go out to meet people. This is working in every community and corner of Europe.
- Rapid testing is important.
- Non-judgmental services. Services provided by community or by very friendly people close to community.
- Confidentiality and anonymity
- Safe environment



# HOW TO REDUCE STIGMA

- Decriminalize drug use, sex work, transmission and exposure to HIV (HepC?)
- People don't do sex because it is healthy; most of its meanings are elsewhere: Sex is pleasurable, it is fun, it is great way of connecting, it is the basis of families...  
Even if sexual health is important, we should shift our focus on positive meanings of sex and sexual pleasure in order to nurture healthier and happier people.
- Everyone has a right to an age-appropriate, culturally relevant, scientifically accurate, realistic and non-judgmental information about sex and sexuality.



# ROMANIA

- Romania needs public policies that support and facilitate the universal access to health for all its citizens, irrespective of their social situation.
- Health and social services must be adapted to the needs of the vulnerable persons and take into account the fact that some of them have multiple vulnerabilities that must be addressed.
- Romania should put into practice the recommendations (WHO, ECDC, UNAIDS) about the demedicalization of testing services, which will create simpler and more accessible services for marginal groups.
- Romanian public authorities, both at the national and local levels, must financially support integrated prevention services that have been put in place with the support of the Global Fund and have proved efficient and adapted to the needs of the target groups.

# WELLBEING ECONOMY

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- Wellbeing is considered to consist of particular individual resources and participation.
- It is important that society can create prospects for wellbeing investments which meet the needs of people efficiently and timely.
- Fortifying civil society and organisations should be central elements in the EU strategy.
- The main goals are wellbeing and good life.
- Working together to build a good life for everyone.

**Test, know your status, get treatment and support.**

➤ **Today's wellbeing is the capital of future wellbeing.**

# THANK YOU!

Everyone who shared their thoughts on stigma as continued barrier to testing for Hep/HIV.

*Criminalisation costs map:*

<http://harmreductioneurasia.org/criminalization-costs/>

*Pictures: Unsplash.com @rawpixel*

[www.hiveurope.eu/Portals/0/HIVStigma\\_Report.pdf](http://www.hiveurope.eu/Portals/0/HIVStigma_Report.pdf)

[www.gnpplus.net/en/programmes/human-rights/plhiv-stigma-index](http://www.gnpplus.net/en/programmes/human-rights/plhiv-stigma-index)