

National Community Action Plan 2017-2020

Sustainable Access to the Continuum of Care in the HIV Context for All in Need in Estonia

Consultation

This draft Plan was developed using the results of the National Consultation of Communities in Estonia on 17-18 November 2016 that gathered 26 representatives from HIV-affected community groups and HIV-service providers. It was a timely event for uniting efforts among an experienced Estonian Network of People Living with HIV (EHPV) and newly-organized groups of communities like LUNEST of people who use drugs and VEK-LGBT of gay and other men who have sex with men, as well as individual leaders of communities and service providers working closely with communities within the context of HIV.

The meeting was organized by the East Europe and Central Asia Union of People Living with HIV (ECUO) in partnership of the Eurasian Harm Reduction Network (EHRN) and in consultation with the EHPV, as part of the Regional Project "[Partnership for equitable access to HIV care continuum in Eastern Europe and Central Asia](#)". Materials of the consultation are available at: <https://www.dropbox.com/sh/azh13lfh1xbypw5/AAAtP5XsMdhirYQtXLnTxkK7a?dl=0>

Ongoing and new assessments presented or mentioned during the Consultation

- [Mapping of the barriers to continuum of HIV care, snapshot of the current situation, resources available and needed for services](#): the draft results were presented by the ECUO and the EHRN at the Consultation and are to be finalized.
- [An assessment of MSM, PWUD and PLHIV community perspectives on priorities of HIV services in Estonia](#) was conducted with the support of a regional project '[Money Can Buy Health If You Budget For It](#)' of the EHRN, ECUO and Eurasian Coalition on Male Health (ECOM) with the Robert Carr Foundation's grant. Those community-identified priorities are yet to be discussed in order to define what changes they recommend and how to translate them into recommendations. The follow-up of the assessment will be supported with three small grants of 20,000 EUR for three community groups in 2017-2018.
- An assessment of access to antiretroviral medications by leaders of people who inject drugs, with the ECUO support.

About the draft Plan and next steps

This document attempts to translate the Consultation's discussions into the format suggested by the ECUO. This version of the Plan cannot be considered final. The participants expressed the need to re-convene and re-adjust the developed ideas for the Plan after each of the community groups would conduct their own individual planning of advocacy and community development separately. In this Plan, the list of suggested priorities and possible milestones for joint advocacy would use re-calibrating with the input of external expert opinion, understanding of the current factual and legal situation, exploration of specific needs of sub-populations by geographical, language/nationality and other criteria and discussing the feasible options of solutions. Additionally, a list of activities, division of roles and timelines would need to be developed.

The draft Plan will be used in early December by the Consultation organizers for a call for proposals from community coalitions that would aim at increasing access to quality and uninterrupted care within the regional project “Partnership for equitable access to HIV care continuum in Eastern Europe and Central Asia”.

The next joint communities meeting where objectives and parameters for collaboration will be reviewed is scheduled in January 2017. In meantime, a Facebook page Estonian Union of HIV Affected Communities (*Эстонское объединение сообществ, затронутых ВИЧ*) will be established for sharing news in Russian, Estonian and English.

Needs and opportunities for the community action

Unlike other countries in the Regional Project, as a high income country and member of the European Union, Estonia does not have a grant from the Global Fund for more than 5 years and is not eligible nearly for any donor support for services, advocacy and community development, beyond EU mechanisms. The country is cited as one of positive examples of taking over funding for services that previously were supported by an HIV grant from the Global Fund, in particular because of the country’s strong commitment to and investment in harm reduction.

Still, Estonia registers the third highest level of new HIV infections registered in Europe, though that level decreased significantly over the last 10 years.¹ HIV prevalence among people who inject drugs is the highest globally, reaching 48.3%.² HIV levels among other key populations are lower: 15.8% among prisoners, 6.2% among sex workers, no data is available for men who have sex with men. The currently prevailing transmission route of the virus is heterosexual. The previous association of the HIV epidemic with the Russian-speaking population who inject drugs and concentration in one hotspot in the Ida-Viru county has a more diverse picture now. The rates of HIV and TB coinfection remain high at 12% and the country is part of the 27 countries with highest burden of MDR-TB globally.³ Prevention among sex workers operates in Tallinn; while work among MSM lacks systematic approach. The projected HIV treatment scale is among the lowest in the European region and with the 63% of late diagnosis among the new cases – the number that is highest within the European Union. The authorities take steps to improve the coverage. For example, they removed a ceiling of funding available for antiretroviral medications in 2017 as part of the country’s commitment to the 90-90-90 goals⁴.

HIV-specific national program, similarly to other diseases, has been integrated in the comprehensive National Health Plan till 2020 (NHP). The NHP is implemented through relevant annual action plans. Currently, there is no multi-stakeholder platform specific to HIV to discuss the progress, challenges and ways to overcome the challenges. Engagement of civil society and community representatives with government structures takes place on *ad hoc* basis. Examples of such engagement are: involvement of different NGOs in a national consultation that resulted in adoption of the 90-90-90 goals; a new working group on updating national HIV treatment protocols where the EHPV and *Convictus Eesti* are asked to nominate their representatives).

¹ European Centre for Disease Prevention and Control, WHO Regional Office for Europe. HIV/AIDS surveillance in Europe 2014. Stockholm: ECDC; 2015.

² UNAIDS Aidsinfo. National data for 2015: HIV PREVALENCE IN PEOPLE WHO INJECT DRUGS. Accessed on 28 Nov. 2016 at: <http://aidsinfo.unaids.org>

³ WHO Epidemiological Profiles of Estonia. Data for 2015 and 2011.

⁴ 90-90-90 goals involve accelerating efforts in order to ensure that 90% of people living with HIV would know their HIV-positive status; among those with known status, 90% would receive antiretroviral therapy and among those on treatment 90% would reach undetectable viral load.

The budget allocated for HIV-specific activities within NHP (beyond purchase of antiretroviral medications) has not changed in 2013-2016. In 2017, there will be a slight increase; this change was planned, justified with specific proposal what it would be allocated for and went through negotiations within the government processes as early as in February 2016.

Aim, objectives and key milestones of the National Community Action Plan

Aim is to strengthen and join community efforts for increasing availability, quality and sustainability of continuum of HIV-related services for all in need in Estonia.

Objective 1: Access to effective services

To support improvement of access to effective, uninterrupted services related to HIV infection

Key milestones

1. Community groups gather data to articulate the needs and most urgent problems including who has the most unequal access to services and special needs. For example, community groups will have an understanding of the needs and current access to services for Estonian-speakers, geographical differences in needs and access to services, and the underlying problems for adherence.
 - a. Community based monitoring of access to antiretroviral medicines (with the support of the ECUO) is finalized in 2017 and community-based monitoring becomes a regular practice.
 - b. Community groups, with the support of the regional networks, has analysis of gaps and different levels of access in terms of geography, community groups and sub-populations, etc.
 - c. Community groups formulate and advocate the recommendations for improving HIV services including based on the prioritization of services conducted in 2016, STIGMA index, the TUBIDU study and other ongoing and future community-based monitoring.
 - d. Community-based monitoring is used by government institutions for defining client/patient needs and quality control at least in one HIV-related service area
2. The HIV treatment guidelines that are being updated in 2016-2017 do sufficiently address the community perspective on such issues as finding of HIV-positive cases that lost contact with health system, linkage of testing and prevention to care and treatment adherence issues. They recommend a stronger role of peer support in those elements.
3. Community-based HIV testing is allowed. [RS comment: the point about self-testing is removed given that the TAI representative confirmed at the meeting that it is legal and is practiced starting from December 2018]
4. Approaches for peer involvement in HIV case finding and treatment support models are identified and agreed to overcome the constrains related to protection of patient data. [RS note: Initially the participants suggested that a solution should be found for health institutions to share patient data with community groups in order to help finding 'lost patients'. Now, this result is re-phrased with the consideration of the comments about the need to investigate further whether this would be feasible, as sharing data would violate the Law on Data Protection; some alternative options of finding practical solutions of peers being on staff and having access to patient data would need to be discussed further]
5. Community advisory boards are established and operate in key cities and regions to address with health professionals the challenges of accessing HIV services for different communities, with consideration of geographic specificities

6. A list of missing standards of provision of HIV-related services is established and reflected in the implementation of the National Health Plan until 2020
7. Updating and development of new standards of HIV-related services involves community representatives.

Objective 2: HIV policy

To facilitate re-establishing of the multi-stakeholder dialogue on improving HIV response with strong presence of the communities

Key milestones

1. Government approves re-establishment of a multi-stakeholder dialogue (council or committee), with involvement of various communities, on HIV is re-established to analyse and agree on the steps for improving HIV response
2. Community groups have their proposals for 2018 and further annual workplans for implementation of the National Health Plan till 2020 (NHP). Those proposals contain justification, expected quantified result and required budget.
3. Community groups effectively use their proposals and influence the processes related to the NHP annual workplans and budget allocation
 - a. At least one or two leaders have a working level of the Estonian language, good knowledge of the workplan- and budget-related processes and engage in different stages of the cycle of planning at the National Institute for Health Promotion (TAI), the Ministry of Social Affairs, during the cross-ministerial discussions and through other stakeholders. This requires advanced planning, e.g. the 2018 planning is largely happening in February 2017.

Objective 3: Stronger communities and collaboration

To strengthen and resource systems of HIV-affected communities for joint advocacy

Main milestones

1. Individual community groups establish their work agendas, are aware of individual community group agendas and support each other.
2. The community groups find a mode of engaging and communication of community leaders from both Russian- and from Estonian-speakers.
3. There are open-face communities' leaders speaking publicly.
4. The Estonian Union of HIV Affected Communities is established, is used by community groups, and has support from external experts and academia.
5. Community leaders are used by Estonian and Russian media as experts on drug policy, HIV and other areas, along with health professionals and others
6. Resources are raised for community development and cooperation. Increased the number of project proposals written by the community groups and their supporters.

Comment:

Only milestones that were articulated as common to all the communities are included in the plan. Other important milestones planned at the meeting were:

- *Adoption of bylaws of the Law on Partnership that would enable a full implementation of gay people right to partnerships*
- *LGBT consultative services are opened in North West of Estonia*

- *Crisis centers for women who use drugs are opened or existing women crisis centers accept women who use drugs, as a result of exposing of violations of rights of women who use drugs*
- *Russian speaking resource on drug policy operates with evidence based information*
- *The regional networks consider exploring the evidence and advocacy opportunities for provision of medical cannabis to HIV-positive patients in need.*