## **Communities map**

## **Community organizing**

The network of people living with HIV, EHPV, is a long-standing organization with a strong record in service provision and engagement in advocating interests of people with HIV. Along with the regional networks, it supports development of other communities. As noted by a number of participants, many of leaders of new community groups have met for the first time at the consultation, which speaks to the recentness of organization of those groups and engagement of new leaders.

The communities' groups are still to finalize their own identities, for example, how to position themselves: more as advocates or focus on service provision, represent certain sub-populations of their communities or grow their membership and knowledge of various sub-groups yet not represented in order to represent the diversity of their communities. They also still need to shape their agendas, and gain a strong analysis of the situation, needs and options for situation improvement and experience in advocacy, as well as build capacity in advocacy which was a new subject for most participants of the Consultation. The participants from different groups were particularly open to learning and understanding each other needs and collaborating with each other, while noting of their differences. Resourcing of activities, currently largely run on volunteer basis and enthusiasm, is a highly sensitive topic, with little funding available for community development or advocacy in Estonia.

The meeting also noted that the groups are largely representing Russian-speakers and communicate in Russian, few know Estonian and only one person with the Estonian language as mother tongue participated at the meeting. While the needs of the Estonian-speaking communities affected by HIV might be similar, however, this is to be established. In the future, special arrangements are needed to ensure the possibility of bilingual communication – Estonian and Russian.

NGOs that provide services to vulnerable populations participated at the Communities Consultation. They may play an important role in community development. On one hand, they can support by linking activists with the NGO clients for identifying and motivating new community leaders and assessing views of those community representatives served by NGOs, also to involve community representatives in service quality assurance, add human rights education and similar important elements to their services. Community peer workers and volunteers are already employed by at least some service providers. Additionally, non-governmental service providers can become partners of community groups in advocacy and share their knowledge and expertise that might be relevant for improving service models and service networking, and on dialogue with authorities.

HIV affected group	Format of community	Activity areas	Key successes	Challenges
People living with HIV (PLHIV)	Estonian PLHIV Network (EHPV), <u>http://ehpv.ee/en/</u> , a national organization legally incorporated in 2005, united HIV-positive people through two level membership.	The strategic plan 2012-2015 identified four priorities: protecting rights and interests of PLHIV, increasing tolerance and solidarity with PLHIV in the society, increasing access to health and non-health services for PLHIV, and development of the network including the professionalism. Strong emphasis on service provision: Until recently – involved in community testing/linkage to care and distribution/promotion of condoms across Estonia and Linda Clinic for treatment with adequate support; it continues provision of psychological, peer social, family, legal and other support, awareness raising in prisons, cultural programs for PLHIV and their families. It plans to strengthen engagement with government, working on allowing community-based testing, coordination of communities, advocacy for funding and development services.	<ul> <li>PLHIV Stigma Index conducted and received a great media and specialist coverage; it led to creation of the Linda Clinic</li> <li>The Network build an 'army of volunteers and peer counselors'</li> <li>Established Forum of Patients (Patient Control) and HIV-TB section</li> <li>Supporting various research projects including TUBIDU around TB among PWUDs and most recent one supported by the regional networks on prioritization of needs of communities</li> </ul>	Loss of 90% of their funding which was used for service provision and also helped to maintain certain networking functions PLHIV community is concerned how to demedicalize testing, link people tested positive with HIV care and to strengthen treatment support with better involvement of peers (including improve the system of allocation of pensions). The Network has limited reach to Estonian community and has limited capacity to work in Estonian. No national HIV-specific plan and platform for engagement with government.
Men who have sex with men (MSM)	VEK LGBT, organised in 2016	The activities of the VEK LGBT are still being planned. Mobilisation of community, increasing capacity of the organisation and development of informal services, as well as cooperation with LGBT rights organisation <i>Eesti LGBT</i> and PLHIV network <i>EHPV</i> are among initial plans.	A great success for LGBT community was the adoption of Law on Partnership. Until recently access to free testing and condoms Establishment of VEK LGBT Supporting the recent assessment by the regional networks on prioritization of needs of MSM communities	The Law on Partnership is not operationalized through the necessary legal bylaws. High closeness of the group because of high stigma and discrimination which lead to low awareness and fears of testing and treatment Fragmentation of the community and lack of NGO working on health Lack of specialized health and psychological care No funding and programs for MSM No access to pre-exposure prophylaxis for HIV (PrEP) and post-exposure prophylaxis (PEP)
People who	LUNEST, established in 2016, currently undergoes legal	More rights awareness and 'street advocacy' and awareness	Documentation of violations of women PWUD rights though no yet	Remaining policing, criminalisation of drug use (drug use is punished by

use drugs (PWUD)	registration. Largely organized by people who are engaged in delivering harm reduction services and HIV field but also there is at least one activist of medical cannabis.	raising of rights of peers and reducing self-stigmatisation Addressing the issues of PWUD access to HIV and other health services Plans working on mobilization of PWUD community including among patients of opioid substitution therapy in Tallinn	impact High commitment to addressing HIV; several issues improved with some doctors (getting virus resistance tests, changing treatment regiment, etc.); a meeting is organised to address the problematic linkage between receiving social benefits (pension) and treatment success. Membership of Estonian speaking medical cannabis advocates Supporting the recent assessment by the regional networks on prioritization of needs of PWUD communities	<ul> <li>penalties and arrest) and high levels of debts of PWUDs and problems with bailiffs.</li> <li>Bad quality of street drugs, with high levels of overdose and limited access to naloxone. Syringes still are not purchased by many pharmacies to people 'looking alike PWUD'.</li> <li>Limited access to ART and hepatitis treatment.</li> <li>Diverse positions of various people who use drugs and those with dependence into the issues, for example, whether drug use per se is a problem. High stigma and self-stigma</li> </ul>
Sex workers	One community leader is undergoing an internship at Silver Rose to understand community development and has potential to work on organization of an initiative group	Not discussed due to lack of representative at the Consultation		
People with or affected by HIV/TB	An initiative group led by one person	Organization of a group and development its activities		
HIV affected women	Not identified as a separate group. HIV-positive women are part of the EHPV			
Teenagers & adolescents	Not identified as a separate group, though one youngster participated in a part of the meeting through the EHPV			