

Co-lead

Strengthening Community leadership for decentralised access to HIV & HCV testing project

Online workshop break-out group reporting HIV/HCV self - testing and community interventions

October-December, 2021

Online workshop break-out group summary | HIV/HCV self-testing and community interventions

On 16 December 2021, the European AIDS Treatment Group (EATG) Alliance for Public Health (APH) and the SOS Project convened a bilingual Russian-English online workshop entitled HIV/HCV self-testing and community interventions as part of the [Co-Lead project](#). The workshop followed research on community perspectives on HIV and HCV self-testing conducted as part of the project. The full research report and Policy brief will be published in early 2022.

This document reports on the presentations, discussion during the meeting and recommendations for follow up outlined by workshop participants.

The aim of the workshop was to provide a platform for community exchange on HIV self-testing (HIVST) and HCV self-testing (HCVST) research and interventions across Europe and Central Asia; as well as sharing of advocacy efforts needed to overcome policy, financial and other practical barriers. It provided a feedback loop on the findings and recommendations emerging from Co-Lead research. Therefore, the meeting started with presentations on some of the latest research emerging in Europe and Central Asia regarding HIV and HCV self-testing at community level.

EATG's Co-Lead Principal Researchers Anna Tokar and Anna Prokhorova summarised project results regarding community perspectives on challenges and opportunities for HIV and HCV self-testing in Armenia, Bosnia and Herzegovina, Kazakhstan, Kyrgyzstan, Poland, Slovenia, and the Russian Federation.

Maria Malakhova presented on the state of play with regards to the roll-out of HIVST in Eastern Europe/Central Asia (EECA), and shared findings and next steps for APH's SOS project.

Danil Nikitin from Global Research Institute (GLORI) then presented results and illustrated the involvement of community in the Foundation for Innovative New Diagnostics (FIND) project assessing the Values and Preferences of HCVST among People Who Inject Drugs in Kyrgyzstan. Stage two of the project, which is expected to conclude in March 2022, will determine the acceptability and feasibility of HCVST among people who inject drugs in Kyrgyzstan.

Niklas Luhmann from WHO HQ presented WHO's 2021 recommendation that HCVST should be offered as an additional approach to HCV testing services and provided a summary of the supporting evidence as well as implementation considerations.

The second half of the workshop was dedicated to breakout groups allowing participants to exchange on A) Policy issues, procurement, pricing and cost or B) Linkage to care and digital tools to support the process. These sessions were facilitated by two EATG members Magda Ankiersztejn-Bartczak (Foundation for Social Education [FES]), and Maka Gogia (Georgian Harm Reduction Network [GHRN]).

The table below reports on key challenges highlighted and recommendation for follow by workshop participants.

Workshop take-away messages	Priorities for action
Community needs	
<ol style="list-style-type: none"> In the Georgian context, MSM and trans populations have been observed to be more engaged in their health. MSM very active to order HIVST online, receive home delivery, follow up, linkage to care, etc. Despite indicating high acceptability of the same HIVST approach provided to MSM, drug users are not as responsive/engaged. Italy and Germany both alluded to community preferences for saliva-based self-tests compared to blood-based. 	<ol style="list-style-type: none"> Consult with key populations in order to best tailor, and adapt as needed, self-testing service delivery based on their needs and preferences. Joint statements/ petitions should be launched to demand ST kit price reduction by manufacturers.

Availability of self-testing diagnostics for HIV and HCV

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| <ol style="list-style-type: none"> 1. HCVST not widely available. Mostly in the context of studies (examples provided from Ukraine and The Netherlands). HCV rapid testing is seen as a medical act in many countries. 2. OraQuick saliva-based HIVST up for approval by Spanish Medicine Agency. 3. Finger-prick HIVST are available in pharmacies (Germany, Ukraine) and via assisted self-testing at CBOs (Ukraine). HIVST kits in Italy available at pharmacies and via vending machines. Platform Prévention Sida (Belgium) to soon start HIVST pilot project. Civil society in Ireland fundraises each year to distribute free HIVST kits during WAD and Pride. | <ol style="list-style-type: none"> 1. Demedicalise self-test diagnostics for HIV and HCV to ease access. 2. Increase promotion where HIVST kits are available (e.g. pharmacies with HIVST having large signage) 3. Look to HIVST research and implementation coming from Germany, Ukraine, Belgium, Ireland and Italy. 4. OraSure HCVST soon to enter the market. High price of HCVST is already anticipated due to smaller market than HIVST. |
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Policy and regulation barriers

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| <ol style="list-style-type: none"> 1. Access and scale-up hindered due to mandatory provider screening, and lengthy registration processes for authorisation/approval of HCVST. 2. Differing regulation between regions and within countries (ie. Spain) regarding pharmacy delivery of HIVST. 3. Resistance from the medical community for both HIV and HCV self-testing 4. Unclear which countries have recommendations on ST included in national HIV and HCV testing guidelines. | <ol style="list-style-type: none"> 1. Good practice in Spain with approval to purchase an HIVST kit without a prescription. The same change is needed for HCVST. 2. Harmonisation of policy and regulation(s) within countries. 3. Broaden dialogue at country level with multi-stakeholders including the medical community, pharmacists, and decision makers. 4. Review national HIV and HCV testing guidelines that includes clear guidance on ST and relevant linkage to care procedures. 5. WHO and NGOs at European level can support NGOs at national level to increase their capacity in ST service, sharing best practices from other countries. |
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Procurement

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| <ol style="list-style-type: none">1. Delays due to registration, cold-chain transport issues, customs clearance, and VAT costs.2. Central/Eastern European and Central Asian countries can only procure HIVST through donor funded projects. Whereas, in Western Europe it is possible to obtain kits online. | <ol style="list-style-type: none">1. Initiate dialogue with self-test manufacturers to address procurement issues and ensure a timely and sustainable supply of test kits to NGOs.2. Engage in a broader dialogue with diagnostics market stakeholders and advocate for affordable and/or free self-test kit distribution to community. |
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Pricing and cost

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| <ol style="list-style-type: none">1. High cost of HIVST kits (ranging from 20 euro in Italy to 37 Euro in Germany). Cost may differ depending on a person's national health insurance status.2. Mention of pharmacies in Spain charging and additional 10-30% to the sale of HIVST kits compared to HIVST kits purchased for professional use.3. Price-volume agreements are challenging for small countries/markets. | <ol style="list-style-type: none">1. Coordinate with partners at local level to mobilise for price reduction advocacy.2. Raise awareness of the importance to have self-testing accessible for key populations at a reduced individual cost.3. Build partnerships with agencies and CSOs at regional level (WHO, ECDC, FIND, UNITAID, EATG, AAE, etc.) as well as governments to put pressure on self-test manufactures to decrease price. |
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Communication with HIV and HCV self-test manufacturers

1. Self-test kit leaflet in relevant language(s).
 2. Self-test kit leaflets lacking local support service contact (webpage, phone number, etc) for more information and linkage to care.
 3. Mention of blood-based HIVST kits only having one lancet provided. There is sometimes need for additional lancet(s) when self-testing.
1. Georgian civil society successfully engaged with a manufacturer to insert a leaflet in Georgian language. This type of action appears to be relatively easy to accomplish.
 2. There is a need to further develop effective communication with manufacturers to routinely update leaflets to include local NGO contact information, linkage to care services, hotline, Q and A sections, and use of QR codes linking to video instructions or consultation.
 3. Advocacy to have manufacturers increase the number of lancets in blood-based self-test kits for HIV and HCV.

Funding and sustainability

1. Availability of self-testing kits in EECA is dependent on donors. Self-testing programmes implemented during Covid-19 within Europe are considered exceptional and not in line with local policies. Questionable whether state programs will sustain procurement given high price of ST kits, thus threatening continuation of ST services.
 2. The direct and indirect costs of self-testing service delivery (cost of self-test kit itself and delivery, advertisement, staffing costs, and maintaining services provided via hotlines and online platforms).
 3. Limited evidence on evaluating the cost-effectiveness of self-testing interventions in the Europe and Central Asia region.
 4. Reluctance of local government to change policies and start programme given limited budget and competing imperatives. This means that HIV/HCV self-testing is not seen as a priority.
1. Budget advocacy activities should be undertaken by CSOs to ensure funding of self-testing interventions after moving to State programme funding.
 2. Budget advocacy should include full services coverage, including full maintenance costs of self-testing interventions.
 3. Use existing self-testing acceptability and feasibility studies for further advocacy to develop self-testing interventions at the local level.
 4. Evaluate cost-effectiveness of self-testing interventions in EECA countries that have varying levels of HIV and HCV incidences.

Pre and post-test counselling

1. Pre/post-test counselling can be a barrier to accessing self-testing. Concerns around sharing identifying information and having to disclose a risky situation.
 2. Low awareness of HIVST, knowledge of HIV in general and the testing window period.
 3. The Covid-19 pandemic interrupted testing service delivery, but also enabled HIVST implementation/expansion. Specific examples provided by Platform Prévention Sida (Belgium) and the Foundation for Social Education (Poland) where optional tester follow-up and anonymous feedback can be done via helpline, SMS, or online questionnaire.
 4. HIV Ireland provides self-testers with options to access additional information and/or counselling via SMS message, phone, and video or audio chatting between 9am-9pm daily. Online resources can be provided to testers in English, Spanish or Portuguese. An online survey is then sent two weeks later for tester feedback -not linked to their result. All is optional for the tester to engage. Despite such efforts, a low feedback response rate has been observed.
1. Pre/post-test counselling for HIVST and HCVST should be optional, with support provided to those who need it.
 2. Remote service (via Zoom, skype) for self-testing process recently rolled out by LILA Milano (Italy). Currently limited capacity for promotion, however a major campaign to come in 2022.
 3. Draw from existing good practices identified by: the Community-based voluntary counselling and testing service network ([COBATEST](#)); and the Joint Action on intergration prevention, testing and linkage to care strategies across HIV, viral hepatitis, TB and STIs in Europe ([Integrate Project](#)).
 4. Important to provide self-testers with multiple channels of communication to provide feedback and access linkage to care, however improving uptake/use of such channels requires further investigation.
 5. Good practice noted from Civil Society in Ukraine of viral hepatitis hotline run by community (women drug users) being trusted and acceptable for community.

Linkage to care

1. Different methods used after a reactive self-test result for HIV or HCV.
 2. Belgian CBO now launching pilot with healthcare providers for same day linkage to care appointments for reactive HCV rapid tests. Partnership also made with HCV network.
1. Suggestion to develop mapping of HIV doctors who can be directly contacted for post-test information, delivery of telehealth appointments, or referral to treatment clinics.
 2. Explore partnerships with patient-led networks, and medical community that is supportive of self-testing interventions.

Digital tools and online ordering

1. Example of [HIVST](#) Finder in Ukraine. Use of social media platforms targeting followers of LGBTQI accounts (Facebook, Instagram, TikTok), campaigns in Ireland found to be successful.
 2. Consideration that while some self-test kits are available for purchase online, they are not always regulated or registered products for self-test use.
1. Data protection to be considered as digital tools expand. One suggestion was to develop an M&E system to track HIVST kit distribution with minimal tester personal data. Generating data to raise awareness and secure future funding.
 2. It was noted that Darknet forums have been used within the EECA region for promotion of self-test finders. This has been found to be effective in reaching recreational or young drug users.



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About the European AIDS Treatment Group:

The European AIDS Treatment Group (EATG) is a patient-led NGO that advocates for the rights and interests of people living with or affected by HIV/AIDS and related co-infections within the WHO Europe region. Founded in 1992, the EATG is a network of more than 150 members from 45 countries in Europe. Our members are people living with HIV and representatives of different communities affected by HIV/AIDS and co-infections. EATG represents the diversity of more than 2.3 million people living with HIV (PLHIV) in Europe as well as those affected by HIV/AIDS and co-infections.

For more information, please visit www.eatg.org