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

Policy and operational brief

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1. About this paper

This policy and practice brief reviews some of the key factors enabling or hinder-
ing availability and integration of HIV and HCV self-testing diagnostics as one of
the ways to advance early diagnosis and linkage to care in most affected popu-
lations, in addition to healthcare provider-initiated testing and testing by trained
lay provider. This paper provides a community perspective drawn from a quantita-
tive and qualitative research piece and an online community exchange meeting.
It outlines opportunities and challenges from a community perspective to inform
planning of self-testing for HIV and HCV service delivery at community level to
ease its access to and uptake by those who would benefit from it. The study has
been carried out in seven countries: Armenia, Bosnia, and Herzegovina, Kazakh-
stan, Kyrgyzstan, Poland, Slovenia, and the Russian Federation.

2. Policy state-of-play and definition of HIV and HCV self-testing

Since 2016, the WHO has recommended HIV self-testing (HIVST) as a safe, con-
venient, confidential, accurate, and effective way to reach people not access-
ing testing services and those would not test otherwise, including key popula-
tions\(^1\)-\(^3\). The first guide on HCV self-testing (HCVST) was released in July 2021\(^4\). It
has been demonstrated that lay users can perform HIVST reliably and accurately
and achieve performance comparable to that of trained healthcare providers\(^1\)-\(^4\).
Thus, HIV self-testing and HCV self-testing is defined in accordance with the WHO
guidelines on self-testing\(^3\)-\(^4\): “A process in which a person collects his or her own
specimen (oral fluid or blood) and then performs a test and interprets the result,
often in a private setting, either alone or with someone he or she trusts.”

3. Healthcare system level: Factors influencing availability of HIV
and HCV self-testing and key recommendations

Policies  According to our research findings, in the majority of studied countries,
HIVST and HCVST policies are either not developed or are developed, but not in-
troduced properly. This is in line with recent WHO’s reporting in the European re-
gion: only 20% of countries have HIVST policy and implementation in place; 14% have no HIVST policy; and 5% have no HIVST policy in development\(^5\). Thus, lack of
a legal framework for HIV/HCV self-testing and/or insufficient implementation of
existing laws on the ground HIVST and HCVST policies might be the fundamen-
tal barrier to the availability of self-testing.
- National HIVST and HCVST policies should be developed and implemented in line with WHO guidelines, and other evidence-based resources.
- Enhance dialogue between community-based/led organisations, healthcare providers, researchers, donors and other stakeholders to create a shared understanding of and roll-out strategy for HIVST and HCVST.
- Introduce and/or promote accessible for all HIVST and HCVST.
- Offline/on-site pre-and post-test counselling should not be mandatory rather additional services.
- Improve current linkage to care algorithm, including confirmatory diagnostics in case of reactive self-test result.
- Further studies (e.g., policy gap analysis) should analyse the gap between HIVST and HCVST policies and how they are exercised in the field. There are discrepancies in how representatives of different groups (e.g., local authorities, healthcare providers, community representatives perceive HIVST and HCVST) perceive implementation or how they think these policies should be implemented in the future.

**Licencing and accreditation** Our study showed that rapid diagnostic tests were rarely recognized by official policies as valid screening diagnostic tool. Moreover, in some countries, the license requirement for performing medical manipulations presents an obstacle to the use of the rapid test diagnostics and defeats the logic behind low-threshold service provision.

- National authorities should approve rapid diagnostic tests to meet different needs of users (e.g., blood, saliva). HIVST and HCVST test results should be recognised by local healthcare providers as screening test result.
- Countries and Donors should support licensing of new self-test kits, including resources such as technical expertise, costs to cover fees, time, etc.
- Self-testing should not employ any accreditation or/and licensing as it should remain a low-threshold service and should be delivered in the framework of the Harm Reduction philosophy.
**Funding** As illustrated by research findings, local authorities have been reluctant to adopt new interventions, such as HIV and HCV self-testing as it would entail funding allocation from the state budget. This position might be explained by governments’ need to address other pressing healthcare and socio-economic challenges at country level (i.e., the response to the SARS-COV-2 pandemic, armed conflicts and internally displaced People in Armenia). Thus, the roll-out of HIV and HCV self-testing as part of the basket of testing options might not be seen as priority for local authorities in light of other emerging and persistent needs in low and middle-income countries, who rely on internationally funded HIV and HCV interventions\[^6\]-\[^7\].

- High cost of self-test kits prevent uptake in most countries across the WHO European region. Discussions must be with manufacturers, wholesalers, pharmacists’ associations, governments, and community centres to address these barriers.
- Community-based organisations should be eligible to receive both local and international funding, and should not face prosecution or any disciplinary measures/sanctions (e.g., “foreign agents”) for accepting international funding.
- National HIVST and HCVST programmes should be adequately resourced by governments to cover the sustained cost of kits and full-service provision.

**Stigma** and discrimination remain a barrier to accessing healthcare services and might hinder demand as well as hamper linkage to care of people performing self-test and receiving a reactive result.

- Meaningful engagement of local communities to address the stigma and discrimination. Criminalization of key populations might be as a trigger/source for social stigma and discrimination.
- Lift discriminatory policies towards key populations; foster procedures granting confidentiality and/or anonymity of patient personal data, including HIV/HCV diagnosis or disclosure of drug use, etc.
- Online ordering via pharmacies and other distant anonymous/confidential approaches might be considered.
- Stigma and discrimination should be additionally examined, in particular it is crucial to understand lived experiences of people facing stigmatization, social exclusion and discrimination.
4. Organisation and individual levels: Factors influencing availability of HIV and HCV self-testing and key recommendations

**Information** We found out that lack of information is one of the cross-cutting barriers, which might hinder HIVST and HCVST availability and accessibility. Local authorities, healthcare providers, community-based organizations and representatives of key populations, might not be aware of and/or not trust in such approaches as HIVST and HCVST.

- Raise awareness about HIVST and HCVST; not only among key populations but also among decision-makers, healthcare providers, and representatives of community-based organizations. Information campaigns should not be limited exclusively to key populations, but testing for all. In this way, information campaigns will contribute to normalisation and might tackle stigma.

- Use clear messaging that promotes a universally understood definition of HIVST and HCVST. Currently, the following terms are often used interchangeably: assisted testing, rapid diagnostics, home-based testing, and self-testing.

- Digital communication platforms and tools (e.i., TikTok, darknet, tinder) might be also considered to inform a large audience about available HIVST and HCVST approached.

- Equip the population with up-to-date, evidence-based information in an understandable format.

- Further studies should also examine views and perceptions towards as well as the implementation of self-testing of the representatives of the key populations in order to meet their needs.

**Digital tools** and remote testing services pandemic context allowed some non-governmental organisations in the region to implement digital and distant services, including testing. This may be seen as a window of opportunity and serve as a case to demonstrate the feasibility of such approaches.
Cases of digital and distant testing should be properly documented and evaluated. Yet we call for a more nuanced examination of these approaches (e.g., cost-effectiveness of these approaches as well as acceptability among key populations). We also stress that the issue of data protection and confidentiality in order to prevent breaches should be addressed additionally, in particular: which and how data should be collected, how to store data, etc.

Consider new digital tools to increase effectiveness of self-testing, including pre- and post-counselling and linkage to care (e.g., QR codes on self-test kits, online support, 24-hours a day hotline etc). Examine programmatic issues needed to be implemented (e.g., M&E procedures, technical skills, personnel, time and special equipment, confidentiality of personal data) as well as cost-effectiveness and approachability and appropriateness of such approaches for the key populations as Internet connection, availability of devices, digital literacy of the users.

To sum up, there are three key domains of barriers to HIV and HCV self-testing that should be tackled first by national, regional and/or local authorities and community-based organisations, in particular:

1. Absence of the legal framework for HIVST and HCVST or its poor implementation on the ground;

2. Lack of funding to implement self-testing with the full-service cycle and/or needed treatment and high cost of kits;

3. Insufficient understanding of the self-testing concept and advantages of self-testing among key populations, local authorities and healthcare providers.

It is crucial to address these barriers concurrently as they are overlapping and interconnected factors. Even though in some contexts community-based organisations and local authorities tackle these barriers across one or two dimensions, it would not be effective unless all three dimensions are considered and engaged simultaneously.
References


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

Co-Lead is a collaborative effort between EATG and FIND, the global alliance for diagnostics.