

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

Findings from qualitative research among key informants in Armenia, Bosnia and Herzegovina, Kazakhstan, Kyrgyzstan, Poland, Slovenia, and the Russian Federation.

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### **Abbreviotions**

**ECDC** The European Centre for Disease Prevention and Control

**EECA** Eastern Europe and Central Asia

**EU** European Union

**HIV** Human immunodeficiency virus

**HCV** Hepatitis C virus

**HIVST** HIV self-testing

**HST** HIV testing services

**IOM** International Organization for Migration

LGBTQI+ Lesbian, gay, bisexual, transgender, queer and intersex

**MSM** Men who have sex with men

**PWUD** People who use drugs

**PWID** People who inject drugs

**SSI** Semi-structured interviews

**SW** Sex workers

**UNAIDS** The Joint United Nations Programme on HIV/AIDS

**VCT** Voluntary counselling and testing

**WHO** The World Health Organization

# 1. RATIONALE

The European AIDS Treatment Group (EATG) is a patient and community-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 160 members from 45 countries in Europe. Members are people living with HIV/AIDS 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 in Europe as well as those affected by HIV/AIDS and co-infections.

In line with EATG's long-term strategy goal to engage, inform and empower all people living with and affected by HIV in increasing the usage of HIV, viral hepatitis, TB, and STI combination prevention and testing strategies in affected communities; EATG is implemented the Co-Lead project 'Strengthening Community leadership for decentralized access to HIV and HCV testing'.

This project focused on community perspectives of HIV and HCV self-testing. It examined how the concept of self-testing is exercised and understood on the ground beyond policy analysis, which might not be able to address lived experiences and persistent facilitators and/or barriers to self-testing in a specific context.

Early HIV/HCV diagnosis continues to be a global health priority, in particular among key populations and Eastern Europe and Central Asia (EECA). Despite efforts to promote and increase the uptake of HIV testing in Europe, it is estimated that it takes on average three years from the time of HIV infection until diagnosis, and every second diagnosed HIV case happens at a late stage (53% of people had CD4 cell count less than 350 cells/mm3 at diagnosis) according to the 2019 surveillance data. In the EECA region, this estimate is a bit higher at 56%. Furthermore, it is estimated that approximately 15–50% of people are unaware of their HIV-positive status across 31 countries of the European Union and European Economic Area (EU and EEA). Eastern Europe and Central Asia remain one of two regions in the world where HIV incidence continues to rise, with a 27% increase in annual HIV infections between 2010 and 2018.

Early HCV diagnosis and care also remains a priority for the WHO European Region, where according to estimate one in every 50 persons are chronically infected with HCV (approximately 14 million people). Countries in the EECA region are reported to have an intermediate and high prevalence of HCV antibodies, while the countries of Western and Central Europe - low.<sup>[3]</sup>

Thus, this study prioritized several, key populations groups (i.e., men who have sex with men (MSM), migrants, people who use drugs (PWUD), and sex workers (SW)), countries in Central Europe, Eastern Europe and Central Asia.

This study was conducted in the WHO European region with four EECA countries (Armenia, Kazakhstan, Kyrgyzstan, and the Russian Federation), three Central/South Eastern European countries (Bosnia and Herzegovina, Poland and Slovenia).

### 1.1. Aim

This piece of research investigated the country-specific policies, regulations, and practical factors that are currently enabling or hindering community-level access to rapid diagnostic tests (RDTs) for self-testing of HIV and/or HCV in seven countries: Armenia, Bosnia, and Herzegovina, Kazakhstan, Kyrgyzstan, Poland, Slovenia, and the Russian Federation.

## 2. METHODS

### 2.1. Theoretical approach: socio-ecological model

The socio-ecological model describes complex associations between policy- (macro), community- and network- (meso) and individual- (micro) level factors and health outcomes. It proposes that individuals' behaviour is determined by factors operating at different levels. These include intrapersonal, interpersonal, community, network, and policy levels (Fig. 2.1.).<sup>[7, 8]</sup> Thus, it provides a framework to describe the interactions of the different levels and to explore factors underpinning inequities and disparities.<sup>[7, 8]</sup>

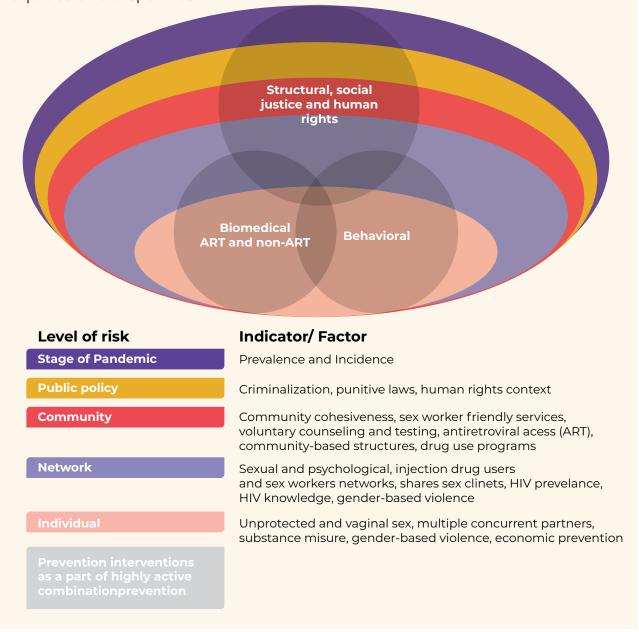


Figure 2.1. Combination prevention: level of risks and prevention interventions. [7, 8]

### 2.2. Defining key terms used

The WHO has recommended HIV self-testing (HIVST) as a safe, convenient, confidential, accurate, and effective way to reach people who may not seek to test themselves and might not be reached out otherwise, including key populations since 2016. [9,10] The first guidelines on HCV self-testing were released in July 2021. [11] It has been demonstrated that lay users can perform HIVST reliably and accurately and achieve performance comparable to that of trained healthcare providers. [9,10]

In this study, HIV self-testing and HCV self-testing is defined in accordance with two WHO guidelines on self-testing: "HIV self-testing and partner Notification" and "Recommendations and guidance on hepatitis C virus self-testing":

"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."

In this study, we use the Joint United Nations Programme on HIV/AIDs (UNAIDS) definitions of MSM, SW, and PWUD:[12]

"The term men who have sex with men describes males who have sex with males, regardless of whether or not they also have sex with women or have a personal or social gay or bisexual identity. This concept is useful because it also includes men who self-identify as heterosexual but who have sex with other men."

"Female, male and transgender adults and young people (over 18 years of age), who receive money or goods in exchange for sexual services, either regularly or occasionally."

"People who inject drugs, or in some situations, a person who uses drugs is a broader term that may be applicable."

We use the International Organization for Migration (IOM) definition of migration;<sup>[13]</sup> thus, we define "migrants" as all persons who moved across an international border or within a state away from their habitual place of residence (where people were born in or spent formative years), regardless of (1) the person's legal status; (2) whether the movement is voluntary or involuntary; (3) what are the causes for the movement; or (4) the length of the stay.

The EU member states and Eastern European countries were determined in accordance with the Schengen Visa Countries List. [14]

### 2.3. Data collection: online mapping survey

In July-September 2021, EATG carried out an online community survey. The overall aim was to map out the current pricing and availability of self-test diagnostics for HIV and HCV in the WHO European region.

Survey questions were reviewed and discussed with EATG members via the EATG's Diagnostics Task Group and community partner organisations before data collection took place between July and September of 2021. The survey was available in Google Form format, in English and Russian (see Annex 1) and contained 15 questions addressed to individuals working in HIV and/or HCV testing service delivery in the region. Responses were kept anonymous, with respondent email addresses collected only for the purpose of clarification as needed.

The survey was promoted by EATG via bilingual (English and Russian) e-mail invitations and social media posts. Communication of the survey explicitly stated that the target respondents were individuals in the region familiar with rapid diagnostic tests (RDTs) for self-testing of HIV and/or HCV. Survey promotion also mentioned that survey findings would inform a qualitative research component to be carried out in autumn 2021.

### 2.4. Data collection: semi-structured interviews (SSI)

To examine the views and perceptions of key informants towards HIV self-testing among key groups, we conducted 18 online SSIs (via Zoom, Skype, and Microsoft Teams) in four EECA and three Central/South-eastern European countries (2-3 SSI per one country): Armenia, Bosnia and Herzegovina, Kazakhstan, Kyrgyzstan, Poland, Slovenia and the Russian Federation. The choice of countries was based on the results of the online mapping survey findings. Countries where there appeared to be limited or less existing data on self-testing for HIV and/or HCV were prioritised. Moreover, these countries represent diverse contexts in terms of HIV and HCV care cascades and policy contexts, including laws and regulations framing HIV and HCV prevention and response among key populations as such policies might be considered repressive towards the target groups.

The researchers identified key informants in close collaboration with EATG's member Diagnostics Task Group and defined them as people, who: 1) are directly involved in the implementation, formation, or in the development of HIV/HCV self-testing intervention or HIV/HCV self-testing policies in a specific country or; 2) have profound knowledge of HIV/HCV testing interventions, including existing challenges towards the introduction of self-testing approaches among key populations in the specific country context.

The participants were recruited purposively (purposeful sampling of qualitative research) in order to include more informative persons with regard to self-testing in a specific context and focus on PWUD, FSWs, MSM, and migrants. Specifically, we included community workers, community volunteers and activists, community researchers, programme managers, heads of organisations.

Key informants were invited via email invitations, describing, in brief, the purpose of the study and contact information.

Semi-structured interviews with key informants were conducted during October 2021 on the basis of the interview guide (Annex 2), which included five key themes: self-testing polices, barriers to HIVST and HCVST, enablers and suggestions on how to improve self-testing approaches and country-specific questions.

All interviews were conducted by trained interviewers (one community researcher, two independent researchers, and one employee of EATG), who prior to the fieldwork received additional training on how to utilize the guideline developed for this study. Interviews were conducted either in Russian or English languages. The duration of the interviews was approximately 60 minutes and no remuneration was provided to interviewees. All interviews were digitally recorded. After each interview, a debriefing form was filled in by the interviewer (Annex 3).

### 2.5. Data analysis: online mapping survey

Responses to the Russian version of the survey were translated by project consultant into English. A descriptive analysis of the full data set, stratified by response per respondent country, was completed.

### 2.6. Data analysis: SSI

All debriefing forms were imported into ATLAS.ti. Data were coded using a modified deductive thematic coding analysis, which was initially guided by the Socio-ecological framework (Figure. 2.1.)<sup>[7,8]</sup>

Two lead researchers read all the debriefing forms, and then in a discussion developed a coding framework (Annex 4: Coding book, Atlas.ti output), which was then applied.

The preliminary findings of the qualitative study were shared with group of community representatives and experts involved in testing service delivery in Europe and Central Asia, and the inputs of this group consultation have been incorporated in this final report.

### 2.7. Ethical consideration: online mapping survey

Consent was implied by the survey respondent continuing to complete the online survey after reading the Google Form introduction text outlining the survey purpose, contact points, handling and reporting of respondent personal data and survey responses, and the planned analysis linked to the qualitative research component. There were no incentives provided to survey respondents.

### 2.8. Ethical consideration: SSI

Verbal informed consent was collected from each participant. All participants were given a detailed description of the study. Depending on the language pref-

erence, the consent form was administered either in Russian or English. All respondents gave informed consent and all the interviews were confidential (the resulting analysis contains no information that links the name of the interviewee or the name of his or her organization to specific statements). Verbal informed consent was obtained from each participant when participants agreed to an audio-recorded interview.

Study participants could choose a convenient time for the interview as well as were advised to utilise some space guaranteeing privacy for the interviewee (e.g., a separate room). All the data were kept safely and only researchers involved in the project had access to it. No remuneration was provided.

### 2.9. Limitations: online mapping survey

The cross-sectional nature of the study survey provides a snapshot of respondent-reported availability and pricing of HIV/HCV self-testing kits; however, no causal inferences can be made with the variables collected. Survey respondents self-selected to participate based on the eligibility criteria and no demographic variables were collected; as a result, the representativeness of our sample could not be measured.

Discrepancies were observed in survey responses from countries with multiple respondents. This could be the result of respondents not understanding survey item(s) and/or simply guessing a response option. This might also reflect the impact of the ebb and flow of self-testing funding opportunities and pilot projects; ultimately making it difficult to unanimously summarize the current state of play. When funding and pilot projects come to a close, it is not uncommon for the availability and distribution of self-testing kits to come to a halt. Not only are key populations and NGOs/CBOs then left without viable alternative self-test options, but this may contribute to the community-level confusion over how self-testing for HIV/HCV is defined.

As this was a self-administrated survey, there is a chance that individuals may have self-screened themselves out of responding due to perceived ineligibility based on their level of involvement, interest and duration of their respective local testing service delivery activities. As a result, non-response bias may have influenced survey findings to only reflect the views of individuals who self-screened to participate. Further, those who did respond to the survey may have responded in a manner to appear more favourable by either under or over reporting the reality of HIV and/or HCV self-testing, introducing social desirability bias.

A descriptive analysis was done to present survey findings, however there was no further analysis to investigate statistically significant associations. This analysis could be achieved in future studies with the use of a standardised and/or validated tool, which would allow for more advanced analysis.

As the survey was only available in online format, this may have contributed to potential sampling bias, as our target sample were key informants who have both internet coverage and high digital literacy.

### 2.10. Limitations: SSI

This study had several limitations, with available time as the primary limitation.

The SARS-COV-2 pandemic resulted in government restrictions, such as social distancing and curfews, which directly impacted the organising and delivery of HIV and HCV related care. In response, there was a shift towards online service provision for some organisations, while service delivery came to a halt for others. To reduce the risk of biased reporting, interviewees asked to refer to both their pre-pandemic and during pandemic experiences. Also, we only conducted this study amongst community-based organisations, which consequently skewed our results to a certain perspective. Overall, our sample in some countries were not diversified enough, and included, for example, only representatives of community-based organizations working with only one key population or only with one type of project (HIV or HCV), which consequently had an impact of overrepresentation of certain group views. The standard thematic analysis process was particularly followed, and the time restrictions caused limitations on thoroughness. We also acknowledge that we did not manage to reach saturation.

In some cases, the sensitivity of the questions may have resulted in social desirability bias and informational bias, though this was partially mitigated by confidentiality. Additionally, questions asking about the past experience may have been skewed by recall bias.

# 3. RESULTS OF THE QUANTITATIVE COMPONENT

### 3.1. HIVST and HCVST availability

There was a total of 70 individual responses to the survey, representing 37 different countries across the region. All respondents identified as either staff or volunteers for local non-governmental organisations (NGOs). 67% (47/70) of respondents completed the survey in English.

Country respondents are presented in Table 3.1 and categorized based on the respondent self-reported local situation availability of RDTs for self-testing of HIV and HCV. The dispersion of country respondents by situation reported are illustrated in Figure 3.1.

An overview of self-test kit manufacturers for HIV are summarized in Figure 3.2. According to survey respondents, the cost of an HIVST kit varied from 0 to 40€, and an HCVST kit ranged from 0,5 to 30€. Survey respondents were asked where one could acquire self-test kits for HIV or HCV in their respective country and to indicate whether these could be obtained for free/no cost or for purchase (see Table 3.2). Survey respondents were asked to report which funding source(s) distribute free HIVST kits (Figure 3.2).

41.4% (29/70) survey respondents indicated no restrictions, or not knowing of any, to acquiring HIV or HCV self-test kits for individual or bulk purchase. The most common barriers identified by respondents as preventing a country from establishing or maintaining self-test options for HIV and HCV are illustrated in Table 3.4.

There was no distinction between HIV or HCV policies during the data collection, and some discrepancies were observed for countries with multiple survey respondents; therefore, there is no separation in the reporting. However, recent publications from INTEGRATE - Joint Action on integrating prevention, testing and link to care strategies across HIV, Viral Hepatitis, TB & STIs in Europe<sup>[16]</sup> and the World Health Organization<sup>[11, 17]</sup> have documented on this matter.

Table 3.1. Survey respondent reporting on availability of HIV and/or HCV self-test kits			
Situation reported	Country		
	Armeniaª		
	Austria		
	Belarus		
Full availability of HIV and/or HCV self-test kits	Estonia		
	Finland		
	Italy <sup>b</sup>		
	Kazakhstan		
	Ukraine		
	Belgium		
	Czechia		
	France		
	Georgia		
	Germany		
	Ireland		
	Kyrgyzstan		
Dautial availability of UIV and/or	Malta		
Partial availability of HIV and/or HCV self-test kits	Norway		
	North Macedonia		
	Poland		
	Portugal		
	Republic of Moldova		
	Slovenia		
	Spain <sup>c</sup>		
	Tajikistan <b></b>		
	UK		

# Albania Bosnia and Herzegovina Bulgaria Croatia Cyprus Greece Iceland Israel Latvia Montenegro Serbia Russian Federatione

Some discrepancies observed between survey respondents reporting on the same country:

- <sup>a</sup> Armenia had four respondents. Two stated only HIVST kit availability, while the other two stated self-test kits for both HIV and HCV were available.
- <sup>b</sup> Italy had four respondents. Three stated only HIVST kit availability, while one stated self-test kits for both HIV and HCV were available.
- <sup>e</sup> Spain had four respondents. Three stated only HIVST kit availability, while one stated only HCVST availability.
- <sup>d</sup>Tajikistan had three respondents. Two stated only HIVST kit availability, while one stated no availability of HIV nor HCV self-test kits.
- <sup>e</sup> The Russian Federation had two respondents. One stated self-test kits for both HIV and HCV were available, while one stated no availability of HIV nor HCV self-test kits.

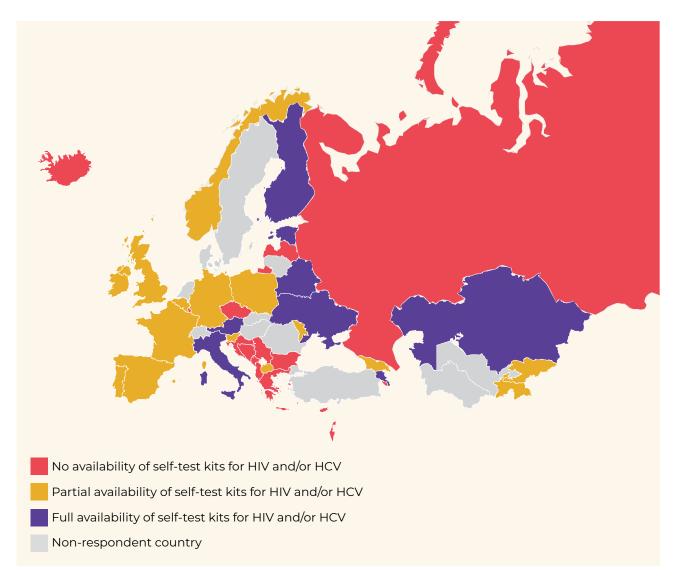


Figure 3.1. Country survey respondents by reported availability of self-test kits for HIV and/or HCV

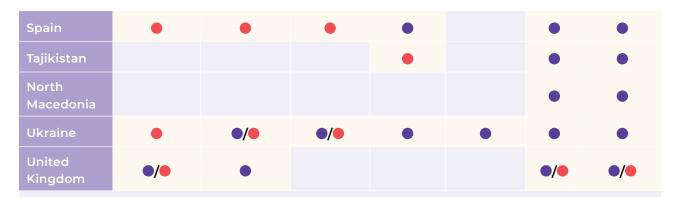
# 3.2. Self-testing kits for HIV and HCV: manufacturers, cost, and distribution

An overview of self-test kit manufacturers for HIV are summarized in Figure 2. According to survey respondents, the cost of an HIVST kit varied from 0 to 40€, and an HCVST kit ranged from 0,5 to 30€. Survey respondents were asked where one could acquire self-test kits for HIV or HCV in their respective country and to indicate whether these could be obtained for free/no cost or for purchase (see Table 3.2). Survey respondents were also asked to report on the funding source for free HIVST kits, if available (see Table 3.3).

# Table 3.2. Distribution of self-test kits for HIV/HCV reported by country respondent

● = free; ● = for purchase; ●/● = distributed for free and for purchase

	Pharmacy	Online (within my country)	Online (outside of my country)	Com- munity Centres	Mobile testing clinics	NGOs	Pilot projects /studies
Albania			•	•	•		•
Armenia					•	•	•
Austria	•	•	•				
Belarus	•	•	•	•	•	•	•
Belgium	•	•	•	•	•	•	•
Bulgaria						•	•
Croatia							•
Czech Republic	•	•	•	•		•	
Estonia		•	•	•	•	•	•
Finland	•		•	•	•	•	•
France	•	•/•	•	•		•	•
Georgia		•	•/•	•	•	•	•
Germany	•		•	•/•		•/•	
Ireland	•						
Italy	•		•	•		•	•
Kazakhstan	•					•	•
Kyrgyzstan	•	•	•	•	•	•	•
Malta	•	•				•	
Moldova	•				•	•	
Norway			•				
Poland		•	•		•	•	•
Portugal	•		•				•
Russian Federation	•	•		•		•	•
Slovenia	•						



n=48. Respondent countries: Armenia, Austria, Belarus, Belgium, Bulgaria, Czech Republic, Estonia, Finland, France, Georgia, Germany, Ireland, Italy, Kazakhstan, Kyrgyzstan, Malta, Norway, Poland, Portugal, Republic of Moldova, Russian Federation, Slovenia, Spain, Tajikistan, The former Yugoslav Republic of Macedonia, Ukraine, United Kingdom.

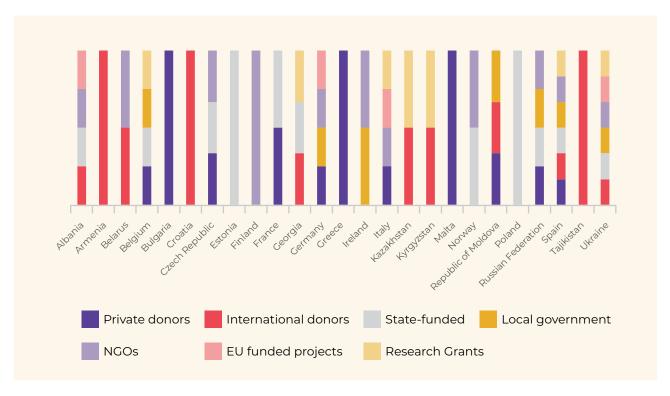


Figure 3.2. Cumulative country respondent reporting of funding sources for free HIVST kits

41.4% (29/70) survey respondents indicated no restrictions, or not knowing of any, to acquiring HIV or HCV self-test kits for individual or bulk purchase. Those who identified such restrictions were often related to issues regarding: lack of government approval and/or financing; testing guidelines that require all testing to be conducted by medical professionals; and expired licensing on registration certified self-test kits for professional use. In addition, the restriction of limited HIVST kit distribution was mentioned by multiple survey respondents, illustrated by examples such as mandatory three-month intervals for one individual to obtain

multiple HIVST kits; minimum age requirements; available exclusively to selected key populations and/or distribution points; and the impact of changes within local political climates on partner countries.

The most common barriers identified by respondents as preventing a country from establishing or maintaining self-test options for HIV and HCV are illustrated in Table 3.3.

Table 3.3. Summary of country respondent reporting on factors preventing a country from establishing or maintaining self-test options for HIV and HCV

try from establishing or maintaining self-test options for HIV and HCV		
Category	Examples	
Community-level factors	<ul> <li>Cost</li> <li>Stigma</li> <li>Lack of awareness</li> <li>Lack of promotion to the general public</li> <li>Poor knowledge of the option</li> <li>Perception that medical professionals do not consider self-testing options as a priority or viewing self-testing as too innovative</li> </ul>	
Administrative factors	<ul> <li>* HIV testing can only take place in clinical settings</li> <li>* Oral swab tests are more expensive that finger prick</li> <li>* Strict regulations and protocol on voluntary HIV testing and counselling</li> <li>* No HCVST policy /unavailable</li> <li>* HCVST kits lacking EC marking</li> <li>* Expansion of HIVST dependent on political will and mass distribution</li> <li>* Lack of appropriate and comprehensive local frameworks for monitoring and referrals</li> <li>* Additional investment in infrastructure and human resources of health authorities to distribute to the general population</li> <li>* HIVST only available during pilots for certain key populations</li> <li>* Local political will to respond to self-testing advocacy efforts</li> <li>* Bureaucracy and "old ways of thinking"</li> </ul>	
Industry-related factors	<ul> <li>* Profit</li> <li>* Perceived lack of demand (as a result of lack of community awareness/education)</li> <li>* Small market</li> <li>* Unclear regulation</li> </ul>	

# 4. RESULTS OF THE QUALITATIVE COMPONENT

# 4.1. Overview of key HIV/HCV self-testing barriers and enablers at the regional level

Lack of comprehensive information, high cost, stigma, and discrimination were reported by study participants to be the major barriers to HIVST and HCVST across three levels: national, organisational, and individual.

### 4.1.1 Information

We found out that lack of comprehensive information about self-testing is one of the cross-cutting barriers, which might hinder HIVST and HCVST availability on national, organizational, and individual levels. Almost all the respondents were speaking about the lack of self-testing promotion among the key populations. For example, in Kyrgyzstan it was illustrated by the idea that the HIV self-test kits are not widely available in the pharmacies because of the absence of customers' demand:

"They are not in pharmacies, most likely because there was no big information campaign. They will just lie there. [Even if test kits appear in the pharmacies, nobody will buy them, because nobody knows about them]"

KG-3

In Armenia interviewees talked about lack of interest to fund informational campaigns about HIV as stakeholders focused on numerical indicators:

"GFATM [The Global Fund to fight Aids, Tuberculosis and Malaria] PR see self-testing only in numbers – here are the tests and give us the indicators. NO funds/budget lines are envisioned for awareness campaigns, even design for leaflets..."

AM-2

Overall, participants of the qualitative study when talking about self-testing frequently referred to other approaches, which also utilize rapid test diagnostics, like VCT, assisted testing or home-testing, testing at mobile clinics or at the community-based organizations. In some cases, the terms "assisted testing" and "self-testing" were used interchangeably by research participants (this study used the WHO definition of self-testing, please see the methods section). Yet, many respondents were aware of the WHO Guidelines on HIVST and HCVST. It is important to men-

tion that the majority of respondents knew about new recommendations and key guidelines in the domain of their expertise as respondents were representatives of community-based organizations key persons motivated and deeply involved in the HIV or HCV response among key populations in their countries.

Furthermore, participants argued that local authorities, including healthcare providers, might not know about, and thus, do not trust in such approaches as HIVST and HCVST.

The majority of the respondents mentioned the importance to raise awareness about self-testing, and that those who need it the most, might simply not know that such an approach is available in their country. The role of informational campaigns was discussed to decrease HIV/HCV stigma, as information should not be limited exclusively to key populations, but prioritise testing for all. Although this research was focused on self-testing barriers and enablers among key populations, the respondents across different countries elaborated on the lack of HIV and HCV-related knowledge among the general population and concerns towards poor sexual health education of young people. Such a situation might lead to the construction and reconstruction of different stereotypes, myths and taboos; and therefore, might affect one's willingness to be tested, including HIV and HCV self-testing. As demonstrated before, stereotypes and misinformation may affect people health behaviour and choices. [15, 18]

### Digital tools

Respondents from the Russian Federation and Poland suggested new digital tools such as QR codes, placed on the self-testing kits could be considered. These QR codes might be used to link patients to the proper pre-and post-testing counselling using videos, text items via Short Message Service (SMS) and social media platforms, or local organisations' websites or HotLines. websites of certain organizations or HotLines. Furthermore, it might increase linkage to care. Such channels might be also considered for notification messages for those who sought or selected the option of post-testing counselling if diagnosed positive.

Respondents from Kazakhstan and Kyrgyzstan were also speaking about the importance of developing a website with high-quality validated information, which should be of use both for the key populations so and the general public.

While the use of digital HIV interventions have been reported in existing literature to be effective among certain populations, [19-21] we were unable to locate any data on digital support tools HIVST and HCVST specific to EECA countries. This should be addressed additionally.

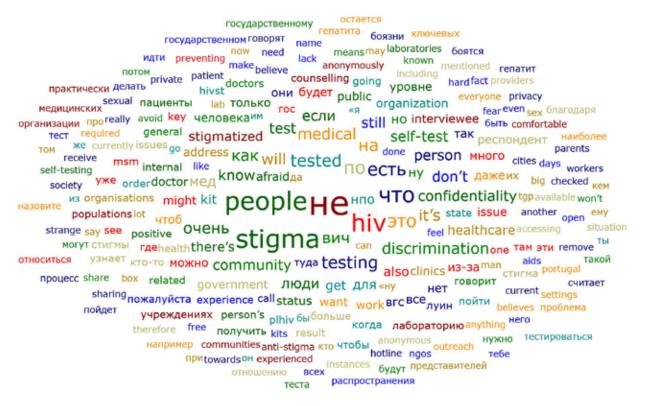


Fig. 4.1.1. Word cloud, Atlas.ti: theme Information

### 4.1.2. Stigma and confidentiality

"The main issues are stigma and how those groups are perceived by society and medical staff."

"...in laboratories the nurses are still a bit biased about [to-wards] key populations. They experience what they call 'stigma' but I would just call it 'inhumane."

KG-2

"People rarely dare to go to buy an HIV test at a pharmacy when there is a high level of stigma and discrimination."

KZ-1

This might be especially the case for **rural areas** far away from the capital cities:

"We are surrounded by some rural areas where self-testing would be problematic... You'll have to figure out where to dispose of this... You have to somehow dispose of this self-test kit. It's a problem... Even privacy can be a problem here because your parents or your partners, or your children or your neighbours will know that you bought a self-test kit in the pharmacy and that you tried to self-test."

KG-2

It is worth mentioning that study respondents differentiated HIV and HCV-related stigmas reporting HIV-related stigma to be more challenging, prevailing and persistent. At the same in Poland, Bosnia and Herzegovina and Slovenia respondents talked about the "normalisation" of discourse around HIV and therefore, a decrease of the fear to get tested on HIV.

Also, there were references made to the higher level of stigma towards LGBTQI+ community members and community-based organizations than towards people who use drugs and organizations serving them, especially cis-gender males.

"It's hard that no one will admit that they are 'members' of the LGBTQ+ population. All of them will say, 'I'm heterosexual, I have a girlfriend'. No one will ever say 'I have a boyfriend, I'm bisexual, I'm homosexual'. That is the first problem."

BA-2

However, in countries like Kyrgyzstan, people who use drugs are highly stigmatized due to the prosecution of the criminal law. All in all, people belonging to several key populations might face more obstacles to access healthcare services,<sup>[22-25]</sup> which also might affect self-testing.

Some respondents focused not only on HIV and HCV-related stigmas or key population-related stigma but on moral values and moral misconducts. According to their thoughts, people don't get tested because it's related to the taboo of sex. Thus, one's sexual behaviours and sexual health are considered to be private topics, not to be discussed openly. In addition, certain sexual behaviours (e.g., same-sex relations) might not be accepted by local communities based on religious norms or even laws, resulting in stigmatised communities hiding their activity for safety. Such examples were provided by respondents from Armenia, Bosnia and Herzegovina, Kyrgyzstan and Poland.

Yet, it was also argued by some respondents that self-testing has potential reach such stigmatised populations, which were not already accessing testing services, and would not be reached with other traditional testing approaches. For example, self-testing was discussed by study participants as a plausible solution for females who are dependent on their husbands/partners and families, or for people who live

far away of the big cities with different clinics and AIDS-Centres, if implemented effectively. Also, some respondents from Slovenia and Kyrgyzstan mentioned that people who use drugs may choose self-tests in order not to visit AIDS-Centres and clinics because of stigmatizing and discriminative attitudes of the medical staff. There was also some discussion on how self-testing might be accessed for those representatives of key populations, who might not be willing to be labelled as key populations when applying for testing to the community-based organizations or specialised clinics, which "all know for whom they are" (KZ-2).

To sum up, all mentioned above may be considered as manifestations of prevailing HIV-related and key population-related stigma, suggesting that governments inaction or introduction of discriminatory laws revealed their social dominance over the "disadvantaged other" or "deviants". [24, 26-29] Key populations are often treated as subordinate "others" who should "be helped" and "saved" (e.g., "culture of care", "rescuing industry"). [29, 30] Thus, in line with previous studies we call for stigma to be recognised not as a matter of an individual process, experience or perception, but rather a social process linked to power, agency, inequality, and exclusion. [24, 26-29] This social process is inherently associated with the production and reproduction of structural inequalities, and should be understood as the social exclusion of people with "unwanted difference" or "deviance" (e.g., "dislike of unlike"), [24, 26-29]



Fig. 4.1.2. Word cloud, Atlas.ti: theme Stigma and Discrimination

### 4.1.3. Costs and other resources

Study participants illustrated how costs and funding played a role across all three levels: national, organisational, and individual levels.

To begin, some participants referred to examples of local authorities' unwilingness to adopt new interventions, like HIV and HCV self-testing, as it would inevitably lead to the necessity to allocate funds from the state budget. Reluctance to fund self-testing implementation on the national level was reported in Armenia, Kazakhstan, Kyrgyzstan, Bosnia and Herzegovina, and Poland.

The situation is even more difficult for the developing countries:

"It's difficult because poverty is everywhere. It seems to me that this economic component has a very strong impact on the results."

KG-3

Respondents also discussed the lack of free HCV and HIV treatment as a possible barrier to self-testing. For example, in Kyrgyzstan participants also talked about the limited access to the ART and sustainability issues as treatment is only partially funded by the local government as well as lack of DAAs. All in all, such testing and care programmes require substantial and continuous state funding.

Also, respondents talked about licensing of the community-based organisation, and that in some cases a special local regulation should be followed or a special permit should be obtained in order to be allowed to perform some medical manipulations; some participants doubted that community-based organisations should even follow procedures to obtain such a license. For example, a respondent from the Russian Federation said that NGOs should not be required to go down the licensing route as it is questioning the philosophy behind harm reduction and low-threshold service provision:

"I do not think that the strategy that envisions NGOs to obtain "medical certificate" for doing testing is relevant. NGOs should be allowed to provide these activities without "medical certificate."

RU-1

Interviewees from Bosnia and Herzegovina, Slovenia and Kazakhstan also discussed that healthcare workers do not consider rapid diagnostic tests to be of sufficient quality, and question the thoroughness of the testing procedure to be performed by the individual alone or ability to read test results correctly:

"The problem with quick tests is that medical experts are against this."

SL-3

Moreover, it is important to mention that even the representatives of the community-based organisations had some concerns towards self-testing approach. For example, in Poland for several years community-based organisations were wor-

ried about post-test counselling, linkage to care and whether the person getting a reactive HIV self-test result would know what steps should be taken next. Respondents from Kazakhstan expressed the same concern. Similarly, one respondent from Slovenia discussed it as follows:

"At first, I was not very in favour of this because I thought there were many obstacles or problems for a person who would self-test and get a reactive HIV rapid test result. But in the end our goal is for people to have the possibility to get tested. So of course, self-testing is one of those methods. As long as there is support for people doing these tests, they have the phone number where they can call for support – if they don't understand the test, if they have a reactive result, if anything is wrong with the test – I'm fine with it."

SL-2

Some participants mentioned that rapid tests should be officially recognised by the state, implying that licensing of new test kits might require additional resources such as technical expertise, costs to cover fees, time, etc.

At the organisational level limited funding, including funding needed to cover supplies, and costs associated with self-testing delivery, including the introduction of new digital approaches, seemed to be barriers. It is important to note that the implementation of the best practices and international recommendations on self-testing in the countries without sufficient support from the governement, by and large, depends on the availability of international funds. The consequence of external aid-dependency and the phenomenon when local governments are reluctant to invest in the HIV and HCV response and it may shift its own resources to other emerging and persistent needs (known as crowding-out effect), [31, 32] for instance COVID-19 or internally displaced persons (IDPs) due to armed conflict in Armenia. Moreover, some respondents referred to the focus on numerical rather than quality indicators. Such phenomena as "data vacuuming" or "audit culture" by stakeholders in health programming reportedly inhibits effective decision-making and outcomes have been documented in other contexts in existing literature. [33, 34] Therefore, this aspect should be further investigated in future studies.

Study participants also discussed how limited financial resources could hinder people from self-testing as they simply might not be able to buy such a test:

"For both key populations and the general population: price."
Price is really the main barrier."

In some countries, self-tests were not available countrywide (for example, in Kazakhstan (HIVST and HCVST) and in Kyrgyzstan people can only buy HIVST kits in the capital and large cities; thus, transport costs might also represent a barrier for those individuals leaving in a rural area with poor or expensive transport connections.



Fig. 4.1.3. Word cloud, Atlas.ti: theme Costs and other resources

### 4.1.4. Other factors

### The SARS-COV-2 pandemic and its impact

The SARS-COV-2 **pandemic** has played a dual role in HIVST and HCVST availability. On one hand, respondents in Kazakhstan, Slovenia, Bosnia and Herzegovina reported that the pandemic affected resources allocation and shifted the focus of national authorities away from innovations that need extra funding, like HIVST and HCVST. Moreover, in many countries' services provided by the local NGOs were stopped or restricted because of the social distancing norms, curfew, and lockdowns and so, those few available HIVST and HCVST services were limited. On the other hand, some participants said that the pandemic context allowed community-based organisations to introduce innovative interventions, including assisted and self-testing. Respondents also reported that it forced organisations to adjust existing services to current pattern with digital or distance interventions utilization. For example, the NGOs in the Russian Federation and in Kyrgyzstan were able to implement an innovative distant video-assisted self-testing, and HIV doctors in Slovenia were able to advocate for HIVST implementation. Moreover, local healthcare providers being busy with COVID-19 patients relied heavily

on community-based organisations. For example, in Kyrgyzstan, NGOs delivered food, syringes, tests and other essentials to representatives of the key populations. In Armenia, self-testing, as well as other services, were introduced via taxi rides among key populations.

Moreover, respondents from the Russian Federation, Poland and Kazakhstan also discussed how the pandemic context enhanced awareness of self-testing among the general population. This might create a supportive environment and assist local authorities to recognise the benefit of implementing HIVST and HCVST in the future. In Poland, NGOs have proven that home-based and distant services provision, including testing, is a feasible target:

"The Covid-19 situation showed that this can be possible... ...we used the Covid-19 to implement this project" [HIVST in April 2022]"

PL-1

Yet, the sustainability of such interventions, especially when there is no legal framework in place is under question. Several recent reports examined digital and remote Harm Reduction support in EECA,<sup>[35-39]</sup> yet the cost-effectiveness of these innovations remain unknown.

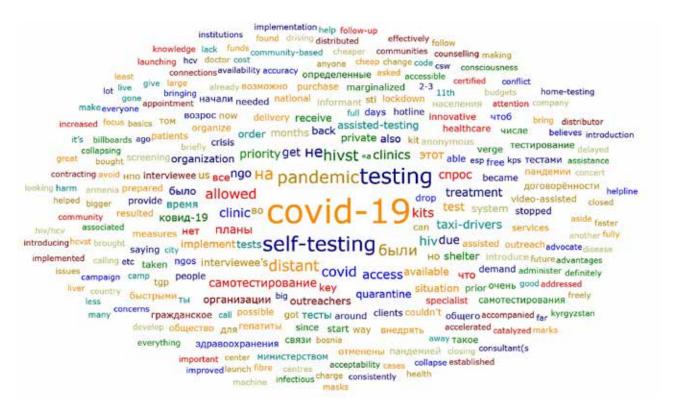


Fig. 4.1.4. Word cloud, Atlas.ti: COVID-19 pandemic

### The socio-political situation in the country

Study participants also shared their views on how the socio-political context in a specific country might either facilitate or obstruct policy development and implementation of certain healthcare innovations. In Poland, Bosnia and Herzegovina and Armenia current political discourse was of concern. For example, in Poland one respondent explained that authorities are not interested in the "sex life" of its citizens, and would be only concerned after someone had been diagnosed; it was perceived by this key informant as a consequence of the "influence conservatism and church". Similarly, respondents from Kyrgyzstan were afraid that the increasing influence of religion on the daily might fuel stigma towards certain populations (e.i., MSM and PLHIV) and sexually transmitted infections, as well as diminish or limit the agency of females in the patriarchal society. [22, 29, 30] Russian respondents elaborated on how hostile so-called "anti-gay propaganda" and "foreign agent" laws affect HIV and HCV programmes by large, and implementations of specific innovations, like HIV and HCV self-testing. Participants from Kyrgyzstan elaborated on how difficult it is to speak publicly about drug use due to the legal framework:

"It is difficult even to speak about our problems publicly, as these words can be turned over as drug propaganda."

KG-3

Interviewees from Armenia discussed the **political influence of the Russian Federation** and expressed concerns over how it might shape local policies in the future. Finally, the influence of the ongoing armed conflict in Nagorno-Karabakh was also addressed by participants (i.e., IDPs, shift of state focus, and funding).

### Migration

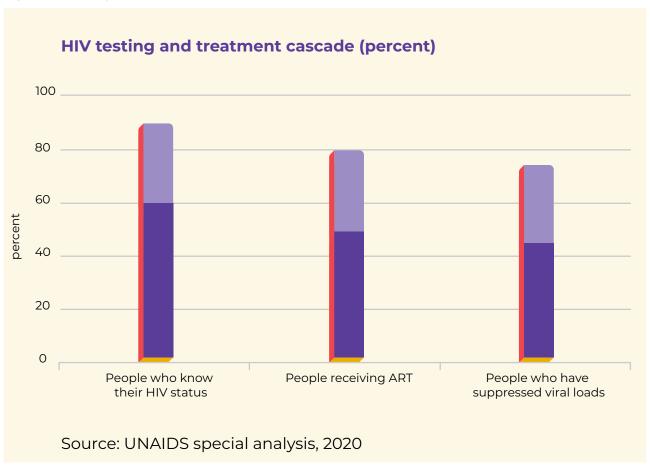
Study respondents discussed how migration status, in particular irregular status, may hamper access to healthcare services, including testing. Interviewees referred to traditional labour migration from Central Asia to wealthier countries like the Russian Federation or Kazakhstan, migration due to the armed conflict in the Nagorno-Karabakh. One respondent from Armenia suggested that the **migrant population** should be prioritised in programming, as there is a labour migration to the Russian Federation and "having sex with other men, contracting HIV and returning to Armenia". In Kazakhstan, respondents proposed that HIV and HCV self-testing should not exclusively target migrants and other key populations, but focus on their families too. In Kyrgyzstan, respondents talked about labour migration to the Russian Federation and limited or lack of access to health services there. Thus, self-testing might be regarded as an additional avenue to reach out to these populations. As demonstrated by previous research, migrant populations might face multiple risks and vulnerabilities and have poor access to healthcare services due to numerous factors (e.g., legal structural barriers, language barrier,

stigma and discrimination, costs, not being able to navigate in the new context, fear etc). [29,30,40-43] Moreover, migrants with irregular status might be forced to stay "invisible" to the state and thus, not be illegible to access healthcare services in the destination country. [29,30,43]

### 4.2. Country-specific findings

### 4.2.1. Armenia

Adult aged 15 to 49 HIV prevalence, 2020 - 0.2 (95% CI: 0.2-0.3%) (<u>UNAIDS, Country factsheet</u>).[44]



National HCV antibody prevalence estimate - 4%.[45]

### 1. Reported self-testing availability:

HIVST kits are available at the community-based organisations, where people can receive pre-and post-testing and counselling and collect rapid test kits to either perform it in the organisation or at home. Yet, the number of tests is limited, that is why this project is not widely promoted. Test type: Oral quick HIV rapid test (saliva based). Not available at health facilities.

HCV-related work, including testing was reported to be weak in the country.

### 2. Reported self-testing policies at the national level:

Participants were unaware of any HIVST or HCVST policies

### 3. Reported self-testing licensing and registration:

Participants were unaware if the tests used for self-testing at the NGOs are officially registered or licensed. Yet, it is believed that it was approved by the state to be used in a "humanitarian aid" capacity.

Also, one respondent elaborated on the **licensing of the laboratories**, which are allowed to perform testing and other manipulations. Such facilities should be registered and have a license and address. This is a difficult process and NGOs cannot get these licenses. This is especially true for blood sample testing, yet it is not clear if other bodily fluids are approved for testing.

### 4. Reported self-testing cost:

No data

### 5. Reported self-testing barriers (national, organizational and individual levels):

**Lack of information** on sexual health and HIV& HCV was seen as a major barrier to self-testing. One respondent was concerned that a person diagnosed positive even with all information in hands will not be able to manage psychologically:

"I think it's a really good option. But from the other side, we need to inform the community and society better because it can create some problem. If for example, someone has a positive test result, it doesn't matter how much information you provide, they may not be psychologically ready for it."

AM-1

Also, respondents talked about the myths and misinformation around sexual health and how it may affect people's health-seeking behaviour and health choices. Furthermore, one respondent pointed to the lack of informational coverage in the media as they are not reporting on the quality of life or what happens to a person after a positive diagnosis. HIV and AIDS appear to be of limited interest to the media, only on Worlds AIDS Day. Participants also connected lack of informational campaigns, poor awareness, and stigma.

**Stigma towards key populations as well as HIV-related stigma** was seen as one of the greatest barriers to access health services. Fear of positive test results and that someone will know it was also named among factors hampering access.

"The main issues are stigma and how those groups are perceived by society and medical staff."

Stigma and discrimination were reported to be especially high towards the LGBTQI+ community. One interviewee believes there is more stigma for a man to disclose having sex with another man compared to disclosure of drug use, when accessing healthcare.

**Lack of confidentiality** was reported to be an issue both at the NGOs and at state health facilities. Consequently, it led to poor or no trust in such organisations. AIDS centres however were believed to be more patient-friendly with better attitudes, but these facilities were geographically harder to reach as they were located in the big cities. Thus, **living in a rural area** might be an obstacle to accessing health-care services, including self-testing.

Also, one respondent suggested that **new M&E policies applied by the MoH and the GF** requiring local NGOs to collect full **personal data** (i.e., Organisations were told they have to provide beneficiaries' full names, addresses, and phone numbers, debriefing form AM-1) of people to whom services were provided and on whom money was spent might be understood by the key populations as breaking their anonymity and confidentiality. Thus, NGOs may resort to twisting reporting in order not to reveal real personal data. Also, it was suggested that donors should focus on the quality-of-service provision and not on the number of services provided as often organisations could be "lying on reporting/monitoring to reach target indicators, but there is no real proof and donors don't seem to really care".

"GFATM [The Global Fund to fight Aids, Tuberculosis and Malaria] PR see self-testing only in numbers – here are the tests and give us the indicators. NO funds/budget lines are envisioned for awareness campaigns, even design for leaflets..."

AM-2

During the lockdown due to **the SARS-COV-2 pandemic**, all services were stopped at the NGOs, still, it was a relatively short period. However, the pandemic also promoted remote or digital service provision. For example, self-testing, as well as other services, were introduced via taxi drivers among key populations.

**Lack of funding** was also reported to be an obstacle as now only several organizations distribute test kits and the number of these kits is limited. Also, difficulties in getting the state to fund activities for people engaged in illegal activities such as sex work, drug users were also highlighted.

One respondent also said that **the armed conflict** might be a barrier as it shifts state attention and funding as well as the priorities of the general population. Also, this event determined a huge flow of both war refugees (internally displaced persons, IDPs) as well as constant flows of seasonal migration waves from this area. So, it is argued that migrants should be recognized and prioritised in the HIV and HCV response strategies.

Finally, the political influence of the Russian Federation and how it might shape the local policies in the future was of concern.

# 6. Reported self-testing enablers and (national, organizational and individual levels) suggestions on how to improve:

Respondents highlighted how important it is to **raise awareness** not only among key populations but also among the general population and properly and timely provide information and link people to the needed services, including post-test counselling.

One respondent suggested that the **migrant population** should be prioritised, as there is a labour migration to the Russian Federation and having sex with other men, contracting HIV and returning to Armenia (debriefing form AM-1).

It was suggested that self-testing approaches **might overcome stigma and lack** of confidentiality barrier and assist people to know their status. Issues of confidentiality should be strengthened and stigma should be addressed overall. **Discriminatory laws** against MSM, sex workers, or people using drugs should be reconsidered (e.g., ban to donate blood for MSM). It was also stressed that civil societies should be more involved in the development of the national HIV or HCV strategies and the cooperation with civil society should be improved.

Self-test kits should be distributed free of charge and **pharmacies** could be considered to do that. **HotLines available 24/7 and a website** and providing counselling were also suggested by respondents. Such services should be offered outside of routine business hours because people would be self-testing at all times of day/night.

**Social media as well as other media** might be used to reach out to a wider audience.

### 4.2.2. Bosnia and Herzegovina

Adult aged 15 to 49 HIV prevalence, 2020 – no data (<u>UNAIDS country factsheet</u>).<sup>[44]</sup>
Treatment cascades no data

Prevalence of HCV antibodies in the general population - 0.29% to 0.89.[46]

### 1. Reported self-testing availability:

Participants reported that self-testing is not available

### 2. Reported self-testing policies at the national level:

Participants reported that there are no policies on self-testing

### 3. Reported self-testing licensing and registration:

Participants reported that self-tests are not registered or licensed in the country.

### 4. Reported self-testing cost:

Not applicable.

It is impossible to buy self-test. It might be possible to buy it in the neighbouring countries, like Serbia and Croatia.

### 5. Reported self-testing barriers (national, organizational and individual levels):

There are **no organisations focusing only the HIV prevention and response**, including stigma related work via campaigns and testing "on the street" on World AIDS Days. Recently an organisation rebranded its name and changed its mission. Therefore, no longer primarily occupied with HIV. This means that there is no organisation doing such work anymore in Bosnia and Herzegovina. Furthermore, the lack of capacity and interest among LGBTQI+ activists to focus on HIV might be an issue.

HIV-related stigma as well as stigma towards key populations were reported to be a major barrier. One participant said that it is still taboo to speak about HIV. Moreover, participants drew examples of the discrimination towards key populations in health facilities. Overall stigma was seen as a fundamental barrier:

"It's hard that no one will admit that they are 'members' of the LGBTQ+ population. All of them will say, 'I'm heterosexual, I have a girlfriend'. No one will ever say 'I have a boyfriend, I'm bisexual, I'm homosexual'. That is the first problem."

BA-2

**Lack of anonymity and direct cost associated** with testing were also reported to hamper access and potentially could affect self-testing, it has been specifically reported for young people:

"Young people don't have a place to go to get tested for free and anonymously; this is one of the biggest reasons why no one in our country goes to check on themselves. Maybe not all, but maybe 95% of them don't go to test at all."

**BA-2** 

Thus, self-testing might help people who are stigmatised and fear reveaingl their HIV status or that they belong to a certain key population. If self-test kits were to be available in pharmacies, one participant was concerned that pharmacists might stigmatise the person accessing this self-test kit and whether or not**confidentiality will be maintained**.

One participant reported that **healthcare workers do not perceive self-testing kits to be of sufficient quality** and push for confirmatory diagnostics to be performed the same as with other rapid testing diagnostics.

**Lack of information** was seen as an obstacle as people might not know that self-testing exists. One participant highlighted that person receiving a positive diagnosismight not know what to do next.

The testing algorithm currently requires patients to wait several days to get their official diagnosis at the health care facilities (e.g., to run all needed tests, and do paperwork). Thus, **waiting time** might serve as a barrier if it also will be the same for self-testing.

It was also suggested that **the administrative/government divisions** within federation "cantons" (understood to mean "provinces") Bosnia and Herzegovina might complicate the implementation of any policy on the ground as it might be then differently exercised. Moreover, there were anecdotes of obstacles with the health-care system canton **restricting dosages of medications**. Issues with medications **shortages with Prep and ART** could also serve as a barrier to access self-testing.

Also, in some **small cities**, there may be a lack of opportunities to get access to testing in medical facilities. Moreover, people **in small cities might be afraid to get tested** as "all know all" and people are afraid that their diagnosis will be revealed.

One participant also talked about different perceptions of the authorities and community-based organisations on different aspects of HIV response, including the quality of ART treatment: officials claim it to be one of the best in Europe while community-based organisations have a different view.

**The SARS-COV-2 pandemic** has been also seen a barrier as it made HIV prevention less of a priority.

Finally, one participant doubted if **the right-wing governing party party** will have any impact on advocacy, but the interviewee believed it is not a problem.

## 6. Reported self-testing enablers (national, organisational and individual levels) and suggestions on how to improve:

Interviewees supported self-testing and were in favour of its implementation. Anecdotally, there is a concern of a high number of undiagnosed individuals for HIV and HCV in Bosnia. Self-testing would be a strategy to reach the undiagnosed:

"Why not? We have self-testing for corona virus. Why shouldn't you test for HIV or Hepatitis C? I mean, it's the same thing as a pregnancy test."

BA-2

As the first initial step, it was suggested **to map the current situation** with testing in the country as well as compare what is written in national strategies with what's actually taking place. Then, the policies should be developed and adopted. All in all, communication with the government should be improved.

Self-testing might **help people who are stigmatised** and afraid to reveal their HIV status or that they belong to a certain key population. One participant also be-

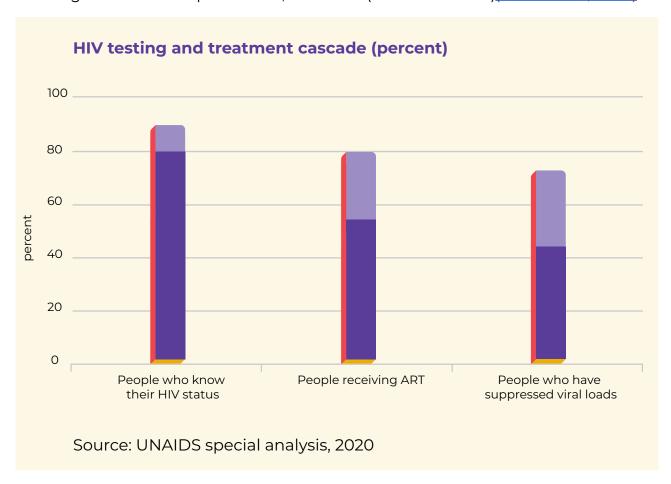
lieved that self-testing could help "develop consciousness" of the general population by normalizing it. For example, these days, people are already doing their own Covid self-tests. Participants suggested that focus should be made on LGBTQI+ community.

Participants described how self-tests could be distributed via **pharmacies**. In such a case, the psychological **support should be provided 24/7** for those who need it. Also, people diagnosed positive should be linked to the care and know what to do next. It was suggested that psychological assistance of those diagnosed should be in place, especially support of **young people**.

It was suggested that **awareness should be raised** as people now do not know about self-testing. Participants also mentioned sexual health education among general populations, so that taboos around sex would be lifted. Increasing media coverage, including TV might be also considered.

#### 4.2.3. Kazakhstan

Adult aged 15 to 49 HIV prevalence, 2020 - 0.3 (95%CI: 0.2-0.4%)(ref UNAIDS, 2020).[44]



National HCV antibody prevalence estimate – 1.5-3%. [45]

HCV prevalence among the general population - 0.7% (95%CI: 0.7-0.8%).[47]

## 1. Reported self-testing availability:

All respondents reported that both HIVST and HCVST are available now or were available in past on the ground:

"A person can go to a pharmacy, buy himself, test himself."

KZ-3

## 2. Reported self-testing policies at the national level:

Participants were not aware of any policies on HIVST and HCVST developed or implemented in the country. One of them mentioned that "self-testing" is not specified anywhere in the legislation or in any regulatory documents. Only express tests had been implemented into the legislation at the national level.

## 3. Reported self-testing licensing and registration:

Participants were not aware if the self-tests are officially registered.

## 4. Reported self-testing cost:

There are both saliva and finger-prick (e.g., blood) HIV rapid tests and only finger-prick tests for HCV. Saliva tests ("Oral Quick") costs about \$10-15 USD, finger-prick tests are cheaper at \$3-4 USD.

## 5. Reported self-testing barriers (national, organizational and individual levels):

Local policies around confirmatory diagnostics are needed for test results to be recognised by the state healthcare providers, and for patients to be eligible to receive HIV or HCV treatment might influence demand for self-testing, as well as decrease "trust" in such methods. Overall, rapid test diagnostics is not considered to be sufficient for obtaining formally accepted diagnoses. One participant even suggested that people will prefer to go directly to the state clinics and test or to the private clinics/laboratories in case of confidentiality concerns, skipping the intermediate step of the rapid test diagnostics in any form (e.g., assisted testing and/or self-testing).

"Self-testing does not give the right to receive, well... treatment. In a medical organization they will force you to pass, they will tell you guys anyway, excuse me, that is, they will all the same make you pass according to the scheme that exists."

KZ-2

It is worth clarifying that there is monopoly on providing HIV testing in Kazakhstan. According to the current legislation, only AIDS-Centres are allowed to conduct HIV testing. This situation inhibits, in particular, the introduction of self-testing, because if even private professional laboratories are not allowed to conduct HIV tests, then it's unlikely for individuals to be allowed to do the tests at home.

Besides low interest of the Ministry of Health in expanding the capabilities of assisted testing and self-testing, there is a belief among healthcare providers and local authorities that rapid testing is sufficient and self-testing are unnecessary.

**Stigma and confidentiality** Participants described cases when people from rural areas and/or small cities were not willing to go to the state clinic or state clinic in their residential area, because of stigma and discrimination. The same situation is relevant for individuals from key populations.

**Costs** Participants mentioned that the pandemic shifted the focus of the government as well as national financial resources away from new projects and policies to be implemented in the country. Thus, self-testing approaches might not be considered as a priority. Furthermore, any new policy developed should have financial means for its implementation, which might keep the government away from introducing this policy:

«If the Ministry of Health issues orders, then, accordingly, it must be understood that the state must support implementation of them."

"If we [NGOs] talk about it now [self-testing], then they [the state], first of all, will start saying "where to get the money?"

KZ-2

Difficulties with **logistics** (e.g., guaranteeing temperature regime for test kits) and **supplies** (e.g., having sufficient stock) was also mentioned among barriers.

**Information** Lack of information about self-testing among communities, activists as well as among policymakers seems to be one of the main barriers. First of all, respondents doubted if healthcare workers recognise the effectiveness of the HIVST and HCVST self-testing or are aware of international guidelines. Secondly, communities and local community-based organizations might mix different approaches using rapid diagnostic kits. And finally, communities, especially migrant populations, might not know of self-test kits being an available option.

**Migrants** It was suggested that such populations as migrants and their families might be excluded from the national healthcare system as they might have residential status, and thus, might not receive free-of-charge healthcare services. On the other hand, these populations might be in more vulnerable positions in terms of health risks (e.g., poor diet, improper living, and labour conditions) and have limited resources (e.g., knowledge of where and how to receive testing services or cost to cover them).

## 6. Reported self-testing enablers and suggestions on how to improve (national, organizational and individual levels):

Overall, participants reported that **uncertainty with the HIVST and HCVST** might be the main fundamental barrier as it should be institutionalised in the country.

Thus, comprehensive implementation of HIVST and HCVST through the national health system, including pharmacies, AIDS-Centres, and local community-based organizations was suggested to be a plausible solution to overcome this barrier. And the development of a large strategic document on expanding access to HIV and HCV testing could become the first step in this process.

Also, HCV treatment availability might facilitate testing at state clinics. It was suggested to raise awareness about HCV treatment availability and also focus informational campaigns on this.

"We can cure hepatitis C, even within the guaranteed volume of free medical care. Free, no problem at all. So, they can test themselves [people perform self-testing]."

KZ-3

The **informational campaigns**, targeting broader populations might not only involve the most vulnerable populations (for example, migrants with irregular status), but also normalise HIVST and HCVST and decrease stigma.

Also, new digital tools such as brief videos on how to conduct tests or how to interpret test results correctly, or providing needed information after positive test results were suggested:

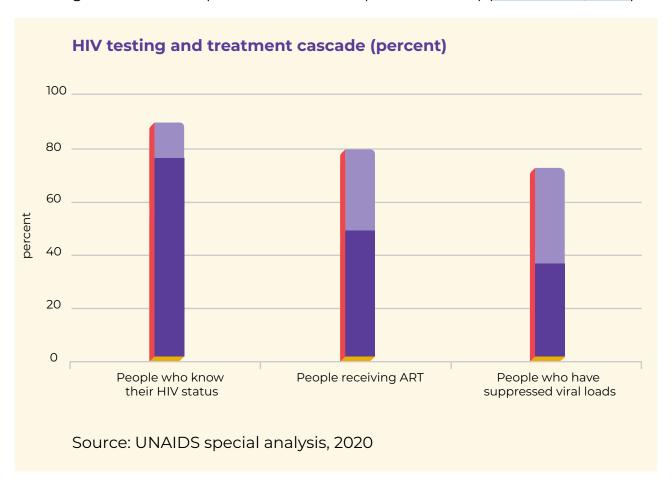
"YouTube, the Internet is full of this stuff, of course. But it's not a fact that the first that [information] that a person will get, is going to be the right one. I am always worried about it."

KZ-3

The key point according to one of the respondents is that self-tests should be available for free or for a nominal **cost** in pharmacies.

## 4.2.4. Kyrgyzstan

Adult aged 15 to 49 HIV prevalence rate 0.2 (95%CI: 0.2-0.2) (ref UNAIDS, 2020).[44]



National HCV antibody prevalence estimate - 4%.<sup>[45]</sup>
HCV prevalence among the general population -2.6% (95%CI: 1.7–3.6%).<sup>[47]</sup>

## 1. Reported self-testing availability:

**HIVST** is available at NGOs and at the AIDS-centers. However, people cannot buy tests at pharmacies.

**HCVST** is not available in Kyrgyzstan. However, HCVST will be available soon as a part of a new pilot project.

#### 2. Reported self-testing policies at the national level:

Respondents reported that there are no clear policies **regulating implementation** of the HIVST and HCVST at the national level. However, there is an order of the Ministry of Health that regulates the "modified community-based distant HIV-testing" that has been implemented as a pilot project during the COVID-19 pandemic. Besides, there is an HIVST protocol that was developed and approved

by the Ministry of Health to be introduced as a pilot HIVST project. Overall, HIVST is considered as a formal part of the comprehensive national testing scheme, yet with poorly defined implementation steps.

## 3. Reported self-testing licensing and registration:

Respondents had different views on the rapid diagnostic test registration. Two of three respondents agreed that HIVST is approved and officially registered. HCVST in contrary was reported not to be registered officially by two respondents. At the same time, the third respondent suggested that the Republican AIDS Centre is about to register or has already registered the HCVST kits.

## 4. Reported self-testing cost:

Self-tests are not available in pharmacies in Kyrgyzstan, that is why respondents were not aware of their price.

## 5. Reported self-testing barriers (national, organizational and individual levels):

**Policies** The self-test procedures are not fully formulated as the national policies, especially in regards to implementation steps.

**Costs** Respondents are talking about costs as a serious barrier to self-testing of HCV. There are no free diagnostics, including needed confirmation testing and treatment of hepatitis C at the governmental level, which can hamper access to testing, including self-testing (for HIV such services have been available for free since 2019). The price of HCV treatment is quite expensive (around USD 500) and not everyone in Kyrgyzstan can afford it (barrier at the macro-level- policy level):

"The treatment has to be available as a next step... To think about just self-testing, it would be unethical if you do not think about the availability of medication for curing HCV."

KG-2

As for now HIVST and HCVST are available only as components of different projects and programs introduced by the local NGOs, and thus, the unstable and unpredictable donor funding of these projects is also one of the key barriers (i.e., the barrier at the meso-level, organisation level).

Respondents also were concerned about pricing of rapid diagnostic tests if they would be available at pharmacies. The prices might end up being much higher than what key populations are willing and able to pay. The direct user-cost would therefore be a barrier (i.e., the barrier at the micro level- individual level).

**Stigma** was reported to be a fundamental barrier to self-testing across different levels: micro-, meso- and macro- levels. For example, one of the respondents talked about invisibility of the PWUD for the Kyrgyzstan authorities:

"It is difficult even to speak about our problems publicly, as these words can be turned over as drug propaganda."

KG-3

All the three respondents elaborated on stigma manifestations at the level of healthcare institutions. People who use self-tests need to confirm their positive results at the AIDS-centres and face a rather discriminative and humiliating procedure there:

"...in laboratories the nurses are still a bit biased about [to-wards] key populations. They experience what they call 'stigma' but I would just call it 'inhumane.'"

KG-2

"If these were self-tests, when you don't have to go to doctors, contact them, and [can just] do this test at home – it would be very attractive."

KG-3

Another significant self-testing barrier is the **absence of a wide information campaign** about self-tests both for key populations and for the general public. There were no promotional or awareness campaigns about self-tests, so only those people who somehow were familiar with the NGOs implementing these projects, could access them.

Meanwhile even representatives of the key populations who are familiar with NGOs and the opportunities, and are more open to self-testing, may be guided away by stereotypes or misinformation. For example, according to our respondents there is a notion among the key populations that the accuracy of the self-test kits is lower than the standard testing. Besides people see potential risk of intimate partner violence and suicide attempts. While there is no single case documenting these risks, such concerns still exist.

When speaking about the general population it is worse to mention a rather low level even of the basic knowledge about HSV and HCV, including available treatment.

"The general public are afraid of being tested. They do not see any particular reason to get tested. They expect to see some signs, symptoms."

## "The general population are scared and think it's [HCV] a fatal disease... Why be tested, if it is not curable?"

KG-2

The situation is complicated by existing taboos of the sexual health topics. Moreover, it was suggested that it becomes harder to talk to people about HIV and sexual health because of the "Islamization processes" that take part in Kyrgyzstan.

## 6. Reported self-testing enablers and suggestion how to improve (national, organizational and individual levels):

The main suggestion on how to improve self-testing in Kyrgyzstan was to make tests **available in pharmacies**. It's important to mention that all the respondents mentioned that the price of the tests shouldn't be very high. Suggested reasonable price - \$5-12 USD. Moreover, interviewees said that it is important to introduce the delivery mechanism with a convenient ordering and buying processes so that these processes would be stigma free.

There also were suggestions on **decreasing stigma**. It is very important to change the confirmation procedure of the positive results at the AIDS-centres and make it more respectful. So, the attitudes of the police officers, medical professionals and government officials to the key populations should be changed. There was even a suggestion to introduce anti-stigma course among healthcare workers as part of their medical training:

"Why not introduce some kind of anti-stigma course in medical academies so that medical professionals who get the diplomas already knowing what 'stigma' really means.... if they are not aware of stigma, they do not know anything about anti-stigma"

KG-2

The respondents spoke about the necessity to provide **efficient and sufficient pre and post-test counselling**. To achieve this aim, training or seminars for the representatives of key population could be organised. However, it would be important to invite people who are trained and perform on the ground pre and post counselling.

Last but not least, detailed **instructions** should be included in the test kits. And such instructions should be both in Kyrgyz and Russian languages. A **well-de-veloped website** with **video tutorials** should be linked from such an instruction.

## 4.2.5. Poland

Adult aged 15 to 49 HIV prevalence, 2020 - no data (UNAIDS country factsheet). [44]

#### Treatment cascades no data

HCV prevalence (HCV RNA+), data provided by national experts—0.4%.[48]

## 1. Reported self-testing availability:

HIVST is available, including the option to buy rapid tests online, but not officially. It's rapid tests that can only be done by a medical provider. Thus, self-testing **remains in a kind of grey zone** in terms of the official regulations in place.

Furthermore, one respondent said that an HIVST project has been running via NGOs since 2020. Also, this project operates at the HIV clinics to distribute HIVST kits to partners of newly HIV-diagnosed patients. For example, one NGO distributing HIVST kits in Poland has reported, that they are distributing free HIVST kits with 1500 test kits sent out currently; 65% of those who ordered HIVST have never tested for HIV before. People might also ask to send them tests via HotLine, where they call to receive consultation after a potential risk exposure or event. Finally, on the mobile van and at the VCT Centres, PWID and MSM are allowed to take away HIVST kits for their sex partners who are not accessing these testing services.

No HCVST in Poland, only rapid HCV tests are available and must be conducted by a medical professional.

Yet, it was suggested that self-testing remains a **grey zone** with rapid HIV tests done outside of a medical setting as they should technically be administered by a medical professional.

## 2. Reported self-testing policies at the national level:

Both respondents were **not aware of official self-testing policies**. One respondent said that there is the official medical definition and the recommendation in the National AIDS Society guidelines indicating that self-tests should be available because it covers those in need at a particular moment and those who might not test otherwise. Another respondent said that there is a reference/ recommendation for affordable or free self-testing for key populations and the general public in the national AIDS strategy, prepared by Polish AIDS Society.

No policy on HCVST

#### 3. Reported self-testing licensing and registration:

One respondent mentioned that only HIVSTs have been registered for testing at home, not HCVST.

## 4. Reported self-testing cost:

HIVST ~20€ and ~25€ (online) and + free through one NGO

HCVST no data

#### 5. Reported self-testing barriers (national, organizational and individual levels):

As there is no legal framework on self-testing adopted in the country as well as

rapid tests should not be used outside of healthcare facility or/and without the involvement of healthcare providers some organisations are then too fearful to provide such services, as it is unclear if they are legally allowed to do so. So, the **legal barrier** was reported to be the biggest challenge for HIVST implementation.

Local authorities seemed not to be concerned about the availability of HIVST as people can buy tests:

"Because we have a private company who sells HIVST kits, stakeholders have the information that HIVST is available in Poland because you can buy it. So, where is the problem?"

PL-1

HIV-related stigma and discrimination towards people undertaking testing in health facilities and **"even in private clinics and laboratories"** were also among barriers to accessing testing. Yet, self-test could in fact overcome it:

"HIV stigma and discrimination in Poland is quite huge."

PL-1

Also, one participant gave examples when people have been tested without their knowledge but with "good" intentions from the medical provider, which then can lead to the dismissal of the healthcare worker who had done this. Moreover, to be employed at a certain job, people might be obliged "to be HIV negative", the interviewee drew an example of police.

The negative perceptions of healthcare workers on self-testing and rapid testing might be a barrier. They argued that it's not an "official" test and that rapid and self-test results should be recorded (signed by a diagnostics expert) and interpreted properly by health professionals. Also, for several years community-based organizations were concerned about post-test counselling, linkage to care and if the person diagnosed positive would know what steps should be taken next. Yet, it seems not to be the case now. One respondent elaborated on the fact that Poland has quite an "old bill" in diagnostics which may be in the midst of an update. One respondent also explained that authorities are not interested in the "sex life" of its citizens, and they would be only concerned after someone had been diagnosed. This was mentioned as a consequence of the "influence conservatism and church".

People might **not be aware of the possibility to choose a self-testing** approach and thus, they do not seek it. As there is no demand or it is not that high, the pharmaceutical companies are not interested to invest money and advertising self-testing. Funds needed to implement self-testing projects (e.g., procurement costs, establishing webpage or Hotline, mailing expenses, equipment, etc) might be a problem for local NGOs. Moreover, the majority of people in Poland think **HIV is "not their problem",** and thus do not apply for testing and might not be interested in self-testing too. Thus, a lack of

HIV-related knowledge might be an obstacle.

**The cost** was seen as a potential barrier to self-test kits available at pharmacies because you must pay to store them there. The direct cost to the patient was also named among potential barriers:

"There is wide consensus among professional, the testers, educators, that self-testing is okay, it's validated. The only question is how to make it available. If it were cheaper it would be better."

PL-2

Also, one respondent reported that women were not considered as a priority group for certain HIV prevention and response strategies in the country, for example, PreP:

"Women are unfortunately totally left out." [in reference to target group for PrEP in Poland]

PL-2

Yet, another respondent said that there are certain interventions targeted on MSM and women, for "Project Tests".

One respondent also suggested that people **living in small villages** might never be tested before and thus, might experience higher levels of stress.

Fear of positive test results and fear of not being equipped to undertake the test alone or interpret the test result correctly could hamper self-testing. Self-stigma if tested positive might be an issue as well.

## 6. Reported self-testing enablers (national, organizational and individual levels) and suggestions on how to improve:

Interviewees suggested that **development and adoption of the effective national policy** (for example the National HIV response plan developed every five years) on self-testing making self-testing and home-testing available at different venues and that municipalities should be included.

There are **online services** to connect people to a variety of healthcare providers for STI and short-term mental health telehealth visits: <a href="www.TyToTu.pl">www.TyToTu.pl</a>. This can webpage is for anyone and it uses gender-neutral language. Such type of platform may be served to promote self-testing projects as well as if needed, link people to other services like counselling and treatments. Respondents suggested that online distribution of self-tests or distribution via pharmacies might be the best venue to go.

Moreover, there was mention of a soon-to-be launched online survey on home

**testing**. The key aim is to advocate for a self-testing approach and collect perceptions of people on pricing and privacy of the home testing approach. Also, it is important **to raise awareness** and if this approach will be accepted by the community and meet their current needs (e.g., are people willing to give their zip code, location, the phone number to get a home test kit, etc). Another respondent argued that it is crucial **to collect data** and show evidence that there is a demand in order to be able to advocate this approach to the government:

"To have the argument and data showing that people need it [HIVST]."

PL-1

It was proposed that sexual education, including HCV and HIV-related knowledge, should be promoted widely. Participants also talked about information campaigns advertising and promoting self-testing as people might not know that this approach exists. Also, it was suggested that participants should know further needed steps to confirm self-testing and receive treatment if needed. Promotion campaigns should address fear-related barriers, for example, fear of positive test results and fear of not being equipped to undertake the test alone or interpret the test result correctly. One respondent also said that currently there is a HelpLine and some online resources, which can support people undergoing self-testing.

It was also suggested to **include information on local HIV or HCV service providers** and available information resources on the test kit and thus, link people to the services they may need:

"If the product has the CE mark, then it is good enough to implement in Poland. But still, I'm aware of other countries where there is a good practice of when you buy a self-test, there is information about NGOs for support. As far as I now, to private company selling HIVST kits [in Poland] is not doing this; there is no helpline or leaflets for you to get more information about HIV... In my opinion, when this kind of product is implemented in a country, they should include information about local organisations where you can find out more information about your HIV-positive result."

PL-1

In relation **to the opening hours** at the state clinic one participant explained that self-testing might be a good alternative to cover the unmet needs of certain groups of patients:

"[the clinic] close[s] at eight, so unfortunately no evening testing."

PL-2

Furthermore, respondents said that **anonymity and simplicity** (one respondent compared it with pregnancy test) of the self-testing approach might be perceived by people as an advantage.

One respondent also thought that **the COVID-19 pandemic** in a way has proven that digital and home-based services are feasible:

"The Covid-19 situation showed that this can be possible... ...we used the Covid-19 to implement this project" [HIVST in April 2022]"

PL-1

Finally, participants talked about **price reduction** (i.e. not more than  $10 \in$ ) or distribution of test kits **for free.** For example, local NGOs implementing HIVST during shutdown bought the tests in the Netherlands as they were cheaper than local Polish products.

Participants also mentioned that there is a need to jointly discuss and advocate for self-testing involving all local NGOs working in the field of HIV and HCV prevention and response, communities of key populations. It is important to build the dialogue with local authorities, healthcare providers, and international agencies via routine meetings and other events.

#### 4.2.6. The Russian Federation

Adult aged 15 to 49 HIV prevalence, 2020 – no data (UNAIDS country factsheet). [44]

#### Treatment cascades no data

National HCV antibody estimate - 4%.[45]

#### 1. Reported self-testing availability:

On one hand, the respondents were speaking about the low availability of self-tests in pharmacies and their high pricing. On the other hand, respondents high-lighted that according to existing legislation, express rapid diagnostic tests can't be used for self-testing. They can only be used under medical supervision which limits access to these tests for the general population. NGOs also need to have medical certificates to provide testing:

'I do not think that the strategy that envisions NGOs to obtain "medical certificate" for doing testing is relevant. NGOs should be allowed to provide these activities without "medical certificate".

RU-1

So, we can assume that even if express tests are available in some pharmacies, legally they can't be used for self-testing. Taking into consideration the fact that express tests' registration is missed this year, it is hard to speak about their availability for the general population.

At the same time, it was reported that several local NGOs implemented pilot projects among MSM. These projects offered self-test kits packed as branded NGO-HIV-boxes that clients could get via delivery service. Moreover, some pilot projects provide distant assisted testing due to COVID-19 restrictions. So, we may say that self-tests are selectively available for representatives of the key populations.

#### **HCV** No data

## 2. Reported self-testing policies at the national level:

All the respondents unanimously spoke about the absence of the regulatory basis for self-testing. However, one of the respondents referred to a positive shift in this direction:

"The only positive shift is that "RosPotrebNadzor" (Russia's key agency responsible for setting epidemiological and sanitarian-hygienic standards) as an independent organ under the President included "self-testing" into their recommendations."

RU-1

## 3. Reported self-testing licensing and registration:

According to one of the respondents both types of rapid test diagnostics, finger-prick, and saliva tests had been available in pharmacies till 2020. However, in 2020 "RosPotrebNadzor" (the key epidemiological control organ of the Russian Federation) prohibited their usage through pharmacy-based distribution as self-testing does not provide "obligatory pre-and post-test counselling". Another respondent said that no finger-prick tests are registered in the Russian Federation now, but there are problems with the saliva "OraQuick" test's re-registration. In any case, the situation with rapid test registration is reported to be disturbing:

"All of us, those working in testing, faced with a real problem when the "OraQuick" producer did not prolong their license in RF in 2021. We are working currently with "OraQuick" tests from 2019, 2020 and by the end of this year they will expire..."

RU-3

#### **HCV** No data

#### 4 Reported self-testing cost:

The current price of the "OralQuick" saliva test is 5,7 USD. Finger-prick HIV test

costs around 2,5 USD.

#### **HCV** No data

## 5. Reported self-testing barriers (national, organizational and individual levels):

**Policies** Absence of the regulatory basis for self-testing was reported as the main barrier. Respondents were speaking about their feeling of the strong opposition from the side of the Ministry of Health and the lack of support on the local level from the AIDS-Centres and other medical institutions.

Research participants also identified their activities as working in a "grey zone" because of the fact that using "OralQuick" out of the healthcare institutions is officially not allowed. They mentioned that many NGOs working in HIV prevention and care in their country are afraid of prosecution sanctions and are not motivated to implement these activities. The **fear of prosecution** leads to the overall passiveness of NGOs and the absence of an active position on self-testing.

On the other hand, one of the respondents mentioned that such a situation of being in a "grey zone" without any regulatory basis for self-testing allows NGOs to be creatively and to launch new projects:

"...In other words, it is quite common for Russia situation when everything that is not prohibited is allowed."

RU-2

**Registration status** of the self-test kits and, consequently, problematic access to these tests in pharmacies should also be identified as barriers for self-testing.

**Low level of understanding** of how self-testing works was also identified as a self-testing barrier.

## 6. Reported self-testing enablers and suggestions on how to improve (national, organizational, and individual levels):

First of all, **clear regulations** and recommendations from the Ministry of Health on self-testing should be implemented. Such regulations will ensure no pressure on NGOs from authorities and zero prosecution risk for their workers.

**COVID-19** pandemic allowed NGOs to implement **remote assisted HIV self-testing**. Self-tests were delivered by post after registration on a website. Then the video-assisted self-testing was organized by NGO's consultants. However, according to our respondents, self-test kits should be **available widely**: not only in NGOs but also in pharmacies. For this to become a reality the **registration status** of the tests should be official.

Informing activities were mentioned as rather important ones. Respondents

were speaking about visible and user-friendly online resources and attractive design of boxes as elements of quality information materials. An interesting and new digital tool such as **QR code was discussed.** QR codes placed on the self-testing kits might be used to link patients to the proper pre-and post-testing counselling.

#### 4.2.7. Slovenia

Adult aged 15 to 49 HIV prevalence, 2020 - no data (UNAIDS country factsheet).[44]

## Treatment cascades no data

Prevalence of hepatitis C virus (HCV) infection among people living with HIV in Slovenia - 14.5% and 10.7%.<sup>[49]</sup>

The presence of an HCV infection was tested in 579/639 (90.6%) patients were confirmed to have HIV reactive test result in Slovenia by the end of 2013. Among them, 7.6% (44/579) of people living with HIV were anti-HCV-positive, and 33/44 (75%) HCV antibody positive patients were also HCV RNA-positive.<sup>[49]</sup>

## 1. Reported self-testing availability:

HIVST used to be available online many years ago. One respondent referenced one case of suicide after a person undertook an HIVST and received a reactive/positive result. Since then, the medical community became concerned and supported the banned free sale of the rapid diagnostic tests. During last 10 years rapid diagnostic tests have not been available for purchase in Slovenia. However, in 2020/2021, due to the WHO HIVST recommendations, tests have been reintroduced to the Slovenian society and now are available for purchase in pharmacies, including online pharmacies.

**HCV** Not available.

#### 2. Reported self-testing policies at the national level:

There are no national guidelines on self-testing.

#### 3. Reported self-testing licensing and registration:

HIV blood (finger pricks) self-test "AutoTest" is legally registered in Slovenia. There are no registered HCVST in this country.

## 4. Reported self-testing cost:

**HIV** €25

**HCV** Not available.

## 5. Reported self-testing barriers (national, organizational and individual levels):

All the research participants talked about existing **resistance towards self-testing** from the authorities and medical society (epidemiologists, infectious disease phy-

sicians, etc). The rapid diagnostic tests are considered not to be precise enough.

"The problem with quick tests is that medical experts are against this."

SL-3

Moreover, it is important to mention that even our respondents – the representatives of NGOs have some concerns about self-testing:

"At first, I was not very in favour of this because I thought there were many obstacles or problems for a person who would self-test and get a reactive HIV rapid test result. But in the end our goal is for people to have the possibility to get tested. So of course, self-testing is one of those methods. As long as there is support for people doing these tests, they have the phone number where the y can call for support – if they don't understand the test, if they have a reactive result, if anything is wrong with the test – I'm fine with it."

SL-2

Based on reported above we may suggest that **the lack of the information** at different levels from authorities and medical society to representatives of community-based organizations might serve as a barrier to self-testing. Furthermore, one respondent suggested that some communities in Slovenia are too focused on other problems and are not interested in getting tested. So, testing should be definitely promoted.

Also, **costs and other resources** were reported as a barrier to self-testing both at the organisational and individual levels. The lack of funding and personnel at the NGOs as well as a rather high price of the test, which might not be affordable for key populations should be seen as barriers to self-testing.

## 6. Reported self-testing enablers and suggestions on how to improve (national, organisational and individual levels):

**The Covid-19 pandemic** may be viewed as an "enabler" of self-testing as in a very tricky way it has promoted and allowed local NGOs to introduce distant and online services, including HIVST. So, as all the institutions were either fully closed during the lockdowns, the implementation of the HIVST had been successfully advocated for. Though, the Covid-19 pandemic restrictions increased access to HIVST by introducing of the HIVST kits for purchase in pharmacies.

The most frequent suggestion on how to improve implementation and uptake of self-testing was that the **price** of the tests should be reduced, and that tests should be offered to the key populations for free. In such a small country as Slovenia if HIVST and HCVST would be available for free all the representatives of key populations could be reached and tested.

Another common suggestion was dedicated to **promotion** of self-testing especially among key populations. Respondents spoke about both online promotion and distribution of the printed flyers, for example, in clinics. Promotional campaigns according to our respondents, should focus on the healthcare providers. Respondents believed that doctors should know that these tests exist and that they are legitimate. Moreover, respondents mentioned that it is important to raise awareness towards HIV and HCV among society in general. According to our respondents, information on HIV and HCV is not widespread in Slovenia, meanwhile it should be widespread so that people are not fearful to get tested or to receive a positive test result.

There also were some practical recommendations. For example, the self-testing **instructions** should be simple, clear, in big printed letters so that people could read them. Each kit should contain a **phone number** of the HelpLine or organization, providing consultations. These should be free of charge peer-support services and anonymous.

Finally, as respondents talked a lot about psychological impact of doing a self-test along, they also mentioned a recommendation to involve NGOs to the **link-age to care process**:

"Patient communities should be there...Linkage to care should be done through the NGOs...you're doing not just linkage to care but also a monitoring process and making sure that people are following the treatment guidelines that are from the medical personnel."

# 5. HIVST AND HCVST AVAILABILITY AND POLICIES: RESULTS OF QUANTITATIVE AND QUALITATIVE COMPONENTS

According to the recent WHO's reporting in the European region: only 20% of countries have HIVST policy and implementation in place; 14% have no HIVST policy; and 5% have no HIVST policy in development.<sup>[50]</sup>

Table 5.1 summarizes our study results of both quantitative and qualitative components as well as it presents recent WHO data on HIVST. We think it is important to highlight discrepancies detected, as it might serve as a proxy indication of insufficient literacy and poor understanding of these approaches on the ground. This data might also be a manifestation of diverse and complex processes of policy formation, adoption, and implementation as well as gaps in these processes. We also suppose that our study participants understood and exercised differently HIVST and HCVST availability and policy existence. While we addressed these issues in previous chapters, we think it is important to mention the inherent heterogeneity of these processes across multiple dimensions, like countries' territories, target populations, etc.

Table 5.1. Summary of HIVST and HCVST availability and policies: comparison of the results of the QN, QL (self-reported data) and WHO data.

Country	QN component		QL component			WHO data	
	HIVST availability	HCVST availability	HIVST availability	HIVST policy	HCVST availability	HCVST policy	HIVST policy
1. Armenia	yes/no	yes/no	yes	no	no	no	implemented
2. Bosnia & Herzegovina	no	no	no	no	no	no	Exist, but not implemented
3. Kazakhstan	yes	yes	partial	no	partial	no	No policy, in development
4. Kyrgyzstan	yes	no	partial	partial	no	partial	Exist, but not implemented
5. Poland	yes	no	yes	partial	no	no	Exist, but not implemented
6. The Russian Federation	yes/no	yes/no	partial	no	no data	no	Exist, but not implemented
7. Slovenia	yes	no	yes	no	no	no	No policy, in development

## 6. RECOMMENDATIONS

The landscape of HIV and HCV testing service delivery models continues to evolve alongside the introduction of novel biomedical technologies and evidence-based testing guidelines. [9,11,16,17,19] As a result, community level and civil society organizations have been equipped with the tools to integrate self-testing service delivery models. By optimizing the use of existing tools and building off of novel testing technologies and approaches, there is a great opportunity to reach and engage key populations with testing offers and access.

In line with some of the existing literature and drawing upon our research findings, we make the following recommendations for countries in Europe and Central Asia:

- 1. Lack of a legal framework for HIV/HCV self-testing or insufficient implementation of existing laws on the ground HIVST and HCVST policies might be the fundamental barrier to the availability of self-testing. National HIVST and HCVST policies should be developed and implemented in dialogue between community-based/led organisations, healthcare providers, researchers, donors and other stakeholders in line with WHO guidelines, and other evidence-based resources. International organisations and donors should recognise HIVST and HCVST as effective, evidence-based diagnostic strategies. Our study found out lots of discrepancies of how HIVST and HCVST policy implementation is perceived by representatives of different groups. This should be examined by further studies (e.g., policy gap analysis), as it is crucial to unpack how HIVST and HCVST policies are exercised on the ground. It is also important to address cost-effectiveness and/or cost-benefit of these approaches in a specific setting.
- 2. It is important to raise awareness about HIVST and HCVST not only among key groups but also among decision-makers, healthcare providers, and representatives of community-based organizations. We also encourage further training on HIVST and HCVST as people use interchangeably terms like assisted testing, rapid diagnostics, home-based testing, and self-testing. Information campaigns should not be limited exclusively to key populations, but testing for all.
- 3. **Meaningful engagement of local communities** to address the stigma and lack of awareness that hinder demand and uptake of self-testing for HIV and HCV.
- 4. Integrate self-testing for HIV and HCV into local testing strategies as one of the testing options, and adequately resourced by governments to cover the cost of kits and full-service provision. HIVST and HCVST test results should be recognised by local healthcare providers as screening test result.
- 5. Regulatory barriers and the 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 regulatory and financial barriers.

- 6. Prevailing stigma and discriminatory politics and practices towards representatives of key populations should be addressed as these remain to be at a high level in the region. Healthcare providers might be prioritized and targeted through mandatory courses during their training at medical universities. Stigma and discrimination should be additionally examined, in particular it is crucial to understand lived experiences of people facing stigmatization, social exclusion and discrimination.
- 7. The SARS\_COV-2 pandemic context allowed NGOs 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. This should be properly documented and used for advocacy purposes, yet we call for a more nuanced examination of these approaches.
- 8. New digital tools might be considered, such as placing QR codes on test kits, which will direct a person to the website with online pre-and post-counselling text or video items, give information on other available services (i.e., HotLines, contact information, and opening hours of community-based organisations, health care facilities, etc). The same technology might be used to link people with healthcare services and/or send notifications for those who agreed. The confidentiality issues should be prioritised, and preferably such applications or web platforms should not collect any personal data or if collected it should not be shared. These approaches also will require additional resources: including technical skills, personnel, time and special equipment. While different digital tools might be an alternative avenue to facilitate HIVST and HCVST, it is important to examine cost-effectiveness and approachability and appropriateness of such approaches for the key populations as Internet connection, availability of devices, digital literacy of the users. Furthermore, these projects should be evidence-based and be informed by the best practices. Finally, M&E procedures should be developed and incorporated into these digital solutions.
- 9. Further studies should also examine views and perceptions towards self-testing of the representatives of the key populations in order to meet their needs as well as digital tools and approaches applied should be considered.

## 7. CONCLUSIONS

According to our research findings, in the majority of studied countries, HIVST and HCVST policies are either not developed or are developed, but not introduced properly. Thus, the lack of a legal framework for HIV/HCV self-testing and/or insufficient implementation of existing laws on the ground suggest that HIVST and HCVST policies might be the fundamental barrier to the availability of self-testing.

Moreover, we found out that lack of comprehensive information as one of the cross-cutting barriers, which might hinder HIVST and HCVST availability on national, organisational, and individual levels. All in all, we this study demonstrated not only the lack of information on the HIVST and HCVST availability, and algorithms to follow, but also poor overall knowledge on HIV/HCV and sexual health among the general population, which might fuel HIV and HCV-related stigma and discrimination.

In addition, study participants illustrated how costs and funding acted across all three levels: national, organisational, and individual levels. High price of self-tests was reported to be the main barrier at the individual level.

Stigma and discrimination remain a barrier to healthcare services and might hinder demand as well as hamper linkage to care of people performing self-test and receiving a reactive result. Prevailing stigma and discriminatory politics and practices towards representatives of key populations should be addressed as these are at a high level in the region.

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

- 1. Absence of the legal framework for HIVST and HCVST or its poor implementation on the ground;
- 2. Lack of sustainable funding to implement self-testing with the full-service cycle and/or needed treatment and high cost of kits;
- 3. And 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.

We also call for further research to focus on: views and perceptions towards self-testing of the representatives of the key populations; lived experiences of people facing stigmatization; social exclusion and discrimination; accessibility and effectiveness of digital and distant approaches applied for self-testing; and cost-benefit and/or cost-effectiveness of HIVST and HCVST across different contexts.

## ANNEX 1. SURVEY QUESTIONNAIRE

## EATG mapping survey on diagnostics for self-testing in Europe

## Google form introduction text:

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 PLHIV and representatives of different communities affected by HIV/AIDS and co-infections.

EATG's Combination Prevention Testing project focuses on access and use of affordable, timely and quality testing tools in community settings. In 2021, EATG decided to focus its efforts to make self-testing of HIV and HCV more accessible.

The aim of this survey is to address the lack of knowledge/awareness of the current pricing and availability of self-test kits for HIV and HCV in the WHO European region. Data collected through this survey will be reported on and disseminated to EATG members and partners in the autumn of 2021.

The results will be used to inform key informant interviews in the autumn 2021 to further investigate regulatory, policy context and practical challenges and solutions from a community perspective.

Your personal data (the email provided) will be treated as confidential. Data collected through this survey will be reported in a way that it cannot be traced back to any individual. Personal contact information will only be used should clarification(s) on information provided be needed.

We thank you in advance for your participation and support. If you have any questions about this survey, please feel free to contact the EATG office: annisabelle. vonlingen@eatg.org or sarah.north@eatg.org.

The survey data collection will close on 10 September 2021.

We ask that you please respond to as many survey questions as possible, in relation to your respective work.

#### Contact email (to be used only if clarification is needed): 1.

Your answer

#### Organisation affiliation (to be used only if clarification is needed): 2.

Your answer

Germany

#### Which country are you reporting for? **3**.

	Albania	Greece	Republic of Moldova
	Andorra	Hungary	Romania
	Armenia	Iceland	Russian Federation
	Austria	Ireland	San Marino
	Azerbaijan	Israel	Serbia
	Belarus	Italy	Slovakia
	Belgium	Kazakhstan	Slovenia
	Bosnia	Kyrgyzstan	Spain
	and Herzegovina	Latvia	Sweden
	Bulgaria	Lithuania	Switzerland
	Croatia	Luxembourg	Tajikistan
	Cyprus	Malta	The former Yugoslav
Czech Republic		Monaco	Republic of Macedonia
	Denmark	Montenegro	Turkey
	Estonia	Netherlands	Turkmenistan
Finland		Norway	Ukraine
	France	Poland	United Kingdom
	Georgia	Portugal	Uzbekistan

## Are self-test kits available, either for purchase or for free, in your country?

Portugal

Yes, but only for HIV
Yes, but only for HCV
Yes, for both HIV and HCV
O No self-testing kits available in my country
Oldon't know

5.	If self-test kits for HIV or HCV are not avechase or for free, why is this the case?	ailable in your o	ountry for pur-
	There is no approved regulation/policy		
	The regulatory/policy approval processed	es are in developi	ment
	There is approved regulation/policy, but	t no company in	the market
	O I don't know		
	Other:		
6.	If HIV self-test kits are sold/distributed are represented? Check all that apply:	in your country,	which brand(s)
	OAAZ		
	O Alere/Abbott		
	Biolytical		
	BioSure		
	OraSure		
	Owen Mumford (ByMe)		
	Other(s):		
7.	If self-test kits for HIV or HCV are availa you acquire or receive these? Check all is a cost or not:	•	• •
		No cost / Free	For purchase
	Pharmacy		
	Online (within my country)		
	Online (outside of my country)		
	Community centres		
	Mobile testing clinics		

8. Are there any other settings where one can acquire/receive a self-test kit for HIV or HCV for no cost or for purchase in your country? If yes, please explain:

Pilot projects/studies

NGO

9.	What is the cost, in Euros, of a self-test kit for HIV in your country?
	If you are unsure of the exact cost, you can state a range (e.g. 10 - 25€).

Your answer

10. What is the cost, in Euros, of a self-test kit for HCV in your country?

If you are unsure of the exact cost, you can state a range (e.g. 10 - 25€).

Your answer

- 11. If self-test kits for HIV are provided for free, how is this financed? Check all that apply:
  - Private donors
  - International donors (e.g.The Global Fund, Unitaid, etc.)
  - State-funded
  - Local government
  - NGO
  - EU funded projects
  - Research grants
  - Other: \_\_\_\_\_
- 12. Are there any restrictions to the acquisition of self-test kits for HIV or HCV in your country, whether for individual kits or in larger quantities? If yes, please explain:

Your answer

13. Has the HIV or HCV self-testing situation changed at all during the

COVID-19 pandemic?				
○ No				
O I don't know				
Yes, distribution of self-test kits has been scaled up				
Yes, regulation for self-testing was advanced				
Yes, regulation for self-testing was achieved				
Yes, more self-test kits are available in more locations				
Yes, more self-test kit options are available				
Yes, reduced pricing of self-test kits				
Yes, increased pricing of self-test kits				
○ Yes, other:				

14. What would you say are the main barriers preventing your country moving forward to establish and/or maintain self-testing options for HIV and/or HCV? Please explain:

Your answer

15. Do you have any additional comments on the topic of pricing and availability of self-test kits for HIV and HCV?

Your answer

# ANNEX 2. INTERVIEW GUIDE: INTERVIEWS WITH KEY INFORMANTS

#### INFORMED CONSENT FORM FOR KEY INFORMANTS' INTERVIEWS

[Please, see instruction for the interviewer in brackets]
[Thank the participant for their time and introduce yourself.]

## **Explain to the participant that:**

- \* You are being invited to take part in a research study, which has the objective of explicitly identifying which structural barriers and facilitators for implementation are present with regard to HIV self-testing and access to care for key populations.
- \* It is important for us to hear about the different experiences, concerns, and suggestions of different people and to learn your opinion with regard to HIV and HCV self-testing.
- \* While we aim to help the community to promote HIV self-testing uptake among key populations in Armenia, Bosnia and Herzegovina, Kazakhstan, Kyrgyzstan, Poland, Slovenia, the Russian Federation, we cannot guarantee that we will be able to cover all of the needs of participants that may be identified during this study.

## Do you have any questions about what I have just explained? Informed Consent:

The interview will take approximately one hour. You will not receive any direct benefit from taking part in this study, however, we hope that the information that you share with us will help to introduce or improve rapid diagnostic tests (RDTs) for self-testing of HIV and/or HCV services among key populations. We would like to record our conversation digitally. Only our researchers will hear or have access to the recording. The resulting analysis will contain no information that links your name or the name of your organization to specific statements. We will keep all data safe.

## Do I have permission to record our conversation?

[Turn on the tape recorder if permission is given. IF NOT, ask the participant to send a text message via email or the application you are using.

Important! Interviewers should collect informed consent via chat of Skype, Zoom, or any other application used or via email; PrintScreen copies should be saved on the Google Drive in the corresponding folder:

All key informants interviewed will be anonymized. No names or organisations should be documented in the interviews or reporting.]

In this interview, I am going to ask you about your opinions with regard to HIV self-testing. Some of the questions may contain sensitive subject matter, and there is no need to share if you are uncomfortable. You are free to stop the interview at any time or to refuse to answer some questions.

Do you agree to participate in the study and to continue the interview?

#### SSI INTERVIEW GUIDE

Interview length: approximately one hour, [Please, see instruction for the interviewer in brackets]

## 1. Icebreaker to begin the conversation

[!Important! Probes to be asked ONLY if the respondent did not talk about this aspect]

## 1.1. Can you briefly tell me about your work?

Probes: Where do you work (country, organizations)? Tell me please about your role?

## 1.2. How does your work involve HIV&HCV testing among key populations? [if they didn't say so already]

Probes: Can you please give examples of how your work (or work of your organization) involves HIV&HCV testing among key populations?

## 2. HIV&HCV Self-testing policies: understanding & definitions, and on-theground implementation

## 2.1. Please, tell how self-testing diagnostics for HIV/HCV is defined in your country [use the name of the country]?

Probes: How do you understand the concept of self-testing diagnostics for HIV/HCV? If there are any official interpretations of the concept of self-testing diagnostics for HIV/HCV in your country [use the name of the country]?

## 2.2. What do you, generally speaking, think about self-testing HIV&HCV approaches?

Probes: What advantages and disadvantages generally do you see in using self-test approaches for HIV or HCV?

What problems could be solved by self-testing diagnostics for HIV/HCV implementation? Why is self-testing not so good in practice? Please recall any specific situations from your working experience when self-testing on HIV/HCV was really helpful or on the contrary lead to problems?

## 2.3. Please describe the situation with HIV/HCV self-testing implementation in your country [use the name of the country]?

Probes: Please, specify if HIV/HCV self-testing policies are established in your country [use the name of the country] at the national level? What do you think of such policies, why? Do you have national guidelines for the use of express-tests (HIV/HCV) in your country [use the name of the country]? Is self-testing included into National guidelines/standards of testing? Is self-test-

ing integrated into existing/more mainstream service delivery models (health-care services)?

Do you know any international policies on HIV and HCV self-testing? If yes, what do you think of them? Do the international policies influence the local context? If Yes, please specify how? Are NGOs and international organizations active and influential in the sphere of HIV/HCV self-testing implementation in your country [use the name of the country]? What do you think of these projects, and why so? What programs or projects related to HIV/HCV self-testing do you know in your country [use the name of the country]? What do you think of these projects, and why so?

## 2.4. Are self-test kits for HIV/HCV available for people in your country [use the name of the country]?

Probes: Are self-test kits for HIV/HCV legally registered as medical products in your country [use the name of the country]? Where and which self-test kits exactly are available (HIV or/and HCV; saliva or/and finger prick; multiplex test kits; which generation of kits being used (Antibody/Antigen): in pharmacies/online/mobile units & clinics in NGO and on its sites (outreach and onsite) / in communities/others)? Please, give me an example.

## 3. Barriers (perceptions on approachability, acceptability, availability, affordability, and appropriateness)

[!Important! Probes to be asked ONLY if the respondent did not talk about this aspect]

Now I would like to discuss barriers to HIV and HCV self-testing in [use the name of the country].

## 3.1. What are the main barriers to self-testing diagnostics for HIV/HCV for key populations in your country?

Probes: What are the main interventions of these programs or projects in the sphere of HIV/HCV self-testing implementation? Which key populations are you working with: men who have sex with men, sex workers, people who use drugs, migrants?

## 3.1.1. Please, tell me about barriers at the governmental/national level? Please, name those important to you. Please, name as many as you can.

Probes: What do you think of policy adoption and implementation of self-test-

ing policies? What do you think about the registration and licensing of self-testing in your country? Procurements? and costs? How do these vary for different key populations? Can you give me an example? Why so?

## 3.1.2. Now let's talk about barriers at the organizational level? Please, name those important to you. Please, name as many as you can.)

Probes: What do you think of service delivery? What do you think of delivery promotion/informing?

And what about linkage to counseling and care, after self-testing? If and how availability of HCV treatment influenced testing? How is that organized in your country? Can you give me an example? In some countries, absence of this linkage is seen as the main argument for not implementing self-testing, what do you think about it?

What do you think about program financing? and monitoring and evaluation? How do these vary for different key populations? Can you give me an example? Why so?

## 3.1.3. What do you think about barriers at an individual level? Please, name those important to you. Please, name as many as you can.

Probes: What do you think of how self-testing is perceived by the communities of key populations? What do key populations think about self-testing? Why so? What about perceived quality, does it seem to be appropriate? What do you think about the direct cost to the user? Can you easily access self-testing (pharmacy, at the NGO)? Are there any regional differences across the country (rural vs urban)? What do you think of the psychological impacts of a reactive/positive result when a person is performing self-testing alone? How do these vary for different key populations? Can you give me an example? Why so?

# 3.2. Could you please recall any specific situations from your working experience which can illustrate barriers of implementation/ maintaining [based on the country context] of self-testing diagnostics for HIV/HCV for key populations in your country?

Probes: Do you know of any coercive self-testing?

#### 3.3. Has something changed during the COVID-19 pandemic?

## 4. Facilitators and plausible ways to improve the current situation

[!Important! Probes to be asked ONLY if the respondent did not talk about this aspect]

## 4.1. Do you have any ideas on how the barriers mentioned above could be overcome?

Probes: Any ideas to improve the current situation on governmental, com-

munity, individual levels would be very helpful.

## 4.2. What are the main successes of the implementation of self-testing diagnostics for HIV/HCV for key populations in your country?

Probes: Please tell as many examples of successful interventions as possible on different levels: governmental, community, individual. How do they vary for different key populations?

## 4.3. Has something changed during the COVID-19 pandemic?

## 4.4. Could you please recall any specific situations from your working experience which can illustrate factors that help the implementation of self-testing diagnostics for HIV/HCV for key populations in your country?

Probes: How does your organization involve the representatives of key populations in self-testing policy formation and promotion of self-testing? Could you recall any successful cases?

## 5. County-specific questions

Context vs policies on HIV and HCV self-testing				
Full availability of HIV and HCV self-test kits: Armenia & Kazakhstan	Partial availability of HIV or HCV self-test kits: Kyrgyzstan, Po- land, Slovenia	No availability of HIV or HCV self-test kits: Bos- nia and Herzegovina & the Russian Federation		
How and what can be improved? Please, give an example of the actions needed. Why?	What should be done to fully establish self-testing policies for HIV/HCV? Please, give an example of the concrete actions needed. Why?	What should be done to introduce self-test-ing policies for HIV/HCV? Please, give an example of the concrete actions needed.Why?		
If you would be in charge of establish- ing HIV/HCV policies in your country what would you do differ- ently? Why?	If you would be in charge of establish- ing HIV/HCV policies in your country what would you do? Why?	If you would be in charge of establishing HIV/HCV policies in your coun- try what would you do? Why?		

Are you aware of any advocacy mechanisms and/or community engagement schemes and bodies into policy development, in particular in sphere oHIV/ HCV self-testing in your country (e.g., coordination mechanism, round tables, national consultations, etc)?

## 6. Concluding the interview

- \* Do you have anything else to add?
- \* Do you want to ask me any questions?
- \* I would like to remind you that this conversation will be kept confidential. We will share the results of this study in RU and EN with all interviewees.

## Thank you for your time!

[!Important! Do not forget to save the recording before ending the session in Zoom/Skype or make sure it will be automatically saved. Please, ASAP put the recording on Google Drive in the corresponding folder and information by the email research team.Please, fill in the Debriefing Form and put it together with the recording on Google Drive]

## ANNEX 3. DEBRIEFING FORM

### DEBRIEFING FORM - Semi-structured Interviews with key informants

Instructions: Please, indicate the country's ISO code, and the number of the interview. The country code can be found below:

Armenia: AM-1

Bosnia and Herzegovina: BA-1

Kazakhstan: KZ-1

Kyrgyzstan: KG-1

Poland: PL-1 Slovenia: SI-1

Russian Federation: RU-1

Name of interviewer:

Date (dd/mm/yyyy):

Country, city (interviewee):

Starting time:

Ending time:

Language of the interview:

#### 1. Which is the profile of the interviewee?

Position, organization, experience, role description

#### 2. Which was the general attitude of the interviewee?

Open/closed, positive/negative, the interviewee was tied or wanted to end up ASAP/ relaxed, the interviewee was worried and felt uncomfortable/ comfortable, the interviewee was distracted/concentrated on the interview

- 3. What went well?
- 4. What did not go so well?

Include logistics, Internet connection, environmental factors, etc.

#### 5. Interviewer's comments

Please, provide any additional valuable observations or comments

#### 6. Key topics discussed

Please, provide a brief summary of the key points mentioned by the interviewee for each of the topics of the guideline listed in the table below. If the interviewee did not provide an answer or the question was not asked (the topic was not discussed), please provide a reason WHY?

N	Topic/ subtopic	Interviewee's response	Interviewer's observations & comments (when applicable)	Citations (when applicable)	Follow-up needed YES/ NO
		Please, provide a key summary	Please, include your observations (e.g., the interviewee did not feel comfortable and did not respond first, only after probing; bad connection)	Please, include a citation when appropriate to better illustrate the findings.	If the top- ic was not addressed or if there were prob- lems with the Inter- net connec- tion, please indicate if it needs to be followed.
1.1.	Can you briefly tell me about your work?				
1.2.	How does your work involve HIV&HCV testing among key populations?				
2.1.	Please, tell how self-testing diagnostics for HIV/HCV is defined in your country?				
2.2.	What do you, generally speaking, think about self-testing HIV&HCV approaches?				
2.3.	Please describe the situation with HIV/HCV self-testing implementation in your country?				
2.4.	Are self-test kits for HIV/HCV available for people in your country?				
3.1.	What are the main barriers to self-testing diagnostics for HIV/HCV for key populations in your country?				
3.1.1.	Please, tell me about barriers at the governmental/national level? Please, name those important to you. Please, name as many as you can.				

3.1.2.	Now let's talk about barriers at
	the organizational level? Please, name those important to you.
	Please, name as many as you
	can.
3.1.3.	What do you think about barri-
	ers at an individual level? Please, name those important to you.
	Please, name as many as you
	can.
3.2.	Could you please recall any spe-
	cific situations from your working experience which can illus-
	trate barriers of implementation/
	maintaining [based on the coun-
	try context] of self-testing diag- nostics for HIV/HCV for key pop-
	ulations in your country?
3.3.	Has something changed during
	the COVID-19 pandemic?
4.1.	Do you have any ideas on how the barriers mentioned above
	could be overcome?
4.2.	What are the main successes of
	the implementation of self-test-
	ing diagnostics for HIV/HCV for key populations in your country?
4.3.	Has something changed during
	the COVID-19 pandemic?
4.4.	Could you please recall any spe-
	cific situations from your working experience which can il-
	lustrate factors that help the
	implementation of self-testing
	diagnostics for HIV/HCV for key
	populations in your country?

5.1.	a. How and what can be improved? Please, give an example of the actions needed. Why?
	b. If you would be in charge of establishing HIV/HCV policies in your country what would you do differently? Why?
	c. What should be done to introduce self-testing policies for HIV/HCV? Please, give an example of the concrete actions needed. Why?
5.2.	a. If you would be in charge of establishing HIV/HCV policies in your country what would you do differently? Why?
	b. If you would be in charge of establishing HIV/HCV policies in your country what would you do? Why?
	c. If you would be in charge of establishing HIV/HCV policies in your country what would you do? Why?
5.3.	a/b/c
	Are you aware of any advocacy mechanisms/community engagement schemes and bodies for HIV/HCV self-testing in your country (e.g., coordination mechanism, round tables, na-

# ANNEX 4. CODING BOOK, ATLAS.TI OUTPUT

Code	Code Group 1	Code Group 2	Code Group 3	Code Group 4	Code Group 5	Code Group 6	Code Group 7	Code Group 8	Code Group 9	Code Group 10
1.1.1. Perceptions towards HIV&HCV self-testing definition in the local policies	(1) Defini- tion HIV self - test- ing									
1.1.2. Perceptions towards HIV&HCV self-testing definition in the program delivery (on the ground)	(1) Definition HIV self - testing									
2.1.1. Policies and guidelines_ National Level		(2.1.) Govern- mental/ national level lev- el_Barri- ers								
2.1.2. Delivery_Na- tional Level		(2.1.) Govern- mental/ national level lev- el_Barri- ers								
2.1.3. Registration and licensing of self-testing		(2.1.) Governmental/national level level_Barriers								
2.1.4. Procurements and supplies		(2.1.) Govern- mental/ national level lev- el_Barri- ers								
2.1.5. Costs_Nation- al Level		(2.1.) Gov- ernmen- tal/na- tional level lev- el_Barri- ers								
2.2.1. Delivery Organization- al level			2.2. Organi- zational level Bar- riers							

2.2.2. Promotion/in- forming Organization- al level	2.2. Organi- zational level Barriers				
2.2.3. Counselling and linkage to care after testing Organizational level	2.2. Organi- zational level Barriers				
2.2.4. Programme financing Organizational level	2.2. Organizational level Barriers				
2.2.5. Monitoring and evalua- tion Organiza- tional level	2.2. Organi- zational level Barriers				
2.2.6. Logistics (2)	2.2. Organi- zational level Barriers				
2.2.7. Passive position of NGOs	2.2. Organi- zational level Barriers				
2.3.1. Perceptions of communities towards self-testing and perceived quality of self - testing Ind Level		2.3. Individu- al - level Barriers			
2.3.2. Direct cost Ind Level		2.3. Individu- al - level Barriers			
2.3.3. Accessibility, regional differences across the country (rural vs urban Ind Level		2.3. Individu- al - level Barriers			
2.3.4. Psychological impacts of a reactive / positive result when a person is performing self-testing alone Ind Level		2.3. Individu- al - level Barriers			
2.3.5. Gender		2.3. Individu- al - level Barriers			
2.3.6. Lack of infor- mation_ind level {3-0}		2.3. Individu- al - level Barriers			

2.3.7. Fear of prosecution		2.3. Individu- al - level Barriers					
2.3.8. Instructions		2.3. Individu- al - level Barriers					
2.3.9. Lack of sup- port on local level from AIDS - cen- ters and other medical insti- tutions		2.3. Individu- al - level Barriers					
2.4.1. Influence of COVID-19 pan- demic			2.4. COVID-19 pandem- ic Barri- ers				
2.5.1. Differences depending on the key popu- lation groups: MSM, SWs, PWUD Bar- riers				2.5. Key pop- ulations Barriers			
3.1.1. Facilitators / enabling fac- tors					3.1. Facilitators and best practices: national, organizational, and individual levels		
3.1.2. Best practices					3.1. Facilitators and best practices: national, organi- zational, and in- dividual levels		
3.1.3. Suggestions on how to improve self-testing					3.1. Facilitators and best practices: national, organi- zational, and in- dividual levels		
3.1.4. Proactive po- sition of NGOs					3.1. Facilitators and best practices: national, organizational, and individual levels		

3.2.1. Influence of COVID-19 pan- demic facili- tators				3.2. COVID-19 pandem- ic_facili- tators		
3.3.1. Differences depending on the key popu- lation groups: MSM, SWs, PWUD Facili- tators					3.3. Key pop- ulations_ Facilita- tors	
4.1.1.E stablished HIV/HCV self - test policies						4.1. HIV test- ing pol- icies Country context
4.1.2. Partially established HIV or HCV self test policies						4.1. HIV test- ing pol- icies Country context
4.1.3. No self - test policies for HIV/HCV						4.1. HIV test- ing pol- icies Country context
Coerced testing						
Religion vs church						
Stigma and Confiden- tiality (3-0)						
War						

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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.

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