



THE PROFILES
OF UNDIAGNOSED HIV
CASES IN UKRAINE

“ IF WE WANT MORE EVIDENCE-BASED PRACTICE,
WE NEED MORE PRACTICE-BASED EVIDENCE ”

(GREEN & GLASGOW, 2006)



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for Public Health

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ABBREVIATION

ANC	Antenatal clinic/care
ART	Antiretroviral therapy
APH	Alliance for Public Health
CITI	Community Initiated Treatment Intervention
HBM	Health Belief Model
HIV	Human Immunodeficiency Virus
IBBS	Integrated Bibehavioral Study
IDU	Injection Drug Use
LTFU	Loss to follow up
MSM	Men who Have Sex with Men
MOH	Ministry of Health
MOT	Modes of (HIV) Transmission
MIS	Medical Information System
OAT	Opioid Agonist Treatment
OCF	Optimized Case Finding
PEPFAR	The U.S. President's Emergency Plan for AIDS Relief. As of time for this report, 12 regions were referred as PEPFAR regions in Ukraine (Dnipropetrovsk region, Donetsk region (government-controlled area), Zaporizhzhya region, Kyiv region, Kyiv city, Kirovohrad region, Mykolayiv region, Odesa region, Poltava region, Kherson region, Cherkasy region and Chernihiv region).
PHC	Public Health Center
PITC	Provider Initiated HIV Testing and Counselling
PLWH	People Living with HIV
PWID	People who Inject Drugs
RT	Rapid test
SCT	Social Cognitive Theory
SN	Social network
SW	Sex Workers
TB	Tuberculosis

METHODOLOGY

STUDY GOAL AND OBJECTIVES

The study goal was an assessment of undiagnosed HIV cases in 12 PEPFAR regions of Ukraine. It included three study objectives:

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- to describe profiles of PLWH who most likely haven't been diagnosed with HIV yet;
 - to define barriers to get these people to HIV care and treatment;
 - to explore motivation factors and facilitators of getting these people to HIV testing and HIV treatment.
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The study had two consequent components: secondary analysis of surveillance data and qualitative part (in-depth interviews with recently diagnosed PLWH).

Secondary data analysis utilized available survey data, routine surveillance and program data:

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- de-identified HIV diagnosis and treatment data for 2010-2018 exported from HIV MIS;
 - 2017 ANC data;
 - 2017 IBBS among PWID;
 - Published survey reports, statistical bulletin, program reports, fact sheets, etc.
 - 2015 IBBS among PWID and their sexual partners;
-

All these data were used to describe groups and their socio-demographic characteristics, to measure correlates that have an association with undiagnosed HIV, to identify geographical areas where undiagnosed cases are more prevalent, etc.

The qualitative part covers the analysis of in-depth interviews. Within this component, we have collected information about several topics:

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- main features of PLWH profiles;
 - facilitators of HIV testing and experience of HIV-positive diagnosis;
 - a social network and support of PLWH;
 - pathways to HIV treatment: barriers and facilitators;
 - knowledge of and barriers to HIV testing before the diagnosis;
 - HIV status disclosure and motivation for HIV testing among social network, sexual and injecting partners;
 - previous history of seeking medical services and HIV testing;
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TARGET GROUPS AND THE SAMPLE SIZE

The target groups of the qualitative part of the study were assigned based on the results of the secondary data analysis. These groups were selected based on the following criteria: (1) sufficient estimated size of undiagnosed HIV cases among these groups; and (2) a lack of information about these groups, their profiles, healthcare motivations, etc., which complicates any effort of service providers to reach these groups.

Additional inclusion criteria were:

- HIV diagnosis within 2017-2019 years;
- aged 18 years or older;
- permanent residence at the study region;
- informed consent to participate in the study.

Table 1 presents the number of interviewed participants within each group category in five regions: Odesa, Kyiv, Dnipro, Mykolayiv, and Zaporizhzhya. Overall, we have enrolled 58 PLWH for the interview.

Table 1. Study groups and number of in-depth interview per study region

	ODESA	KYIV	DNIPRO	MYKOLAYIV	ZAPORIZHZHYA	TOTAL
HIV-positive people who inject drugs (PWID)	1	1	1	1	1	5
Social network of PWID (e.g., sexual partners, friends who use non-injection drugs, etc.)	2	2	2	1	1	8
HIV-positive former PWID (e.g. patients of rehab clinics, friends of PWID)	2	2	2	2	2	10
Male PLWH aged 35-55 years with low CD4 level at the time of HIV diagnosis	3	3	3	3	3	15
Female PLWH diagnosed at the time of pregnancy in 2017-2019	2	2	2	2	2	10
PLWH diagnosed within provider initiated testing in medical facilities (PITC) (excluding key populations: PWID, MSM, SWs)	2	2	2	2	2	10
TOTAL	12	12	12	11	11	58

DATA COLLECTION PROCEDURES

Study team

Qualified interviewers with appropriate experience and knowledge of the study topics conducted in-depth interviews. All interviewers had been trained about study procedures, filling of the study instruments, ethical issues and confidentiality procedures of data management.

Conditions

The duration of the interviews was up to 60 minutes. Interview sites were negotiated with participants during the recruitment process. All sites were comfortable and convenient for participants, had proper conditions to guarantee privacy and safety.

Study participants were recruited by health workers or social workers from local NGOs who provide HIV care or case management to study participants.

All study participants received monetary compensation of \$10 for their time and transportation costs.

ETHICAL CONSIDERATIONS

Recruiters briefly informed potential participants about the study topic and procedures.

Before the interview, all participants had been informed once again about study topics, procedures, potential threats and benefits, the voluntary participation in the study and the right to withdraw from the study at any moment, etc.

All participants have provided verbal informed consent to participate in the study. Study team decided to use verbal informed consent to minimize the risk of confidentiality breach, as the signed informed consent was the only document that could identify a person within the study (regulations 46.117(c) (i) (ii) (Office for Human Research Protections & U.S. Department of Health & Human Services, na)).

DATA MANAGEMENT AND ANALYSIS

All interviews were coded and de-identified. If any names, addresses or dates of birth have been mentioned during the interview, they were changed or deleted from the transcripts.

We have used MAXQDA version 12.13.6 for thematic analysis of transcripts.

STUDY TIMEFRAME

The study was conducted in June-September 2019. Data processing, interview transcription, coding and analysis were done in October 2019-January 2020.

PROFILES OF UNDIAGNOSED PLWH

This section of the report combines findings from secondary data analysis and in-depth interviews. Secondary data analysis is intended to answer the questions about the estimated size of undiagnosed HIV cases for some groups and factors associated with undiagnosed HIV status. In-depth interview analysis is going to describe and explore common trends in profiles of PLWH who have been diagnosed recently. Such analysis is based on the assumption that PLWH who have not been diagnosed yet might have similar profiles to those PLWH that have been diagnosed recently.

PEOPLE LIVING WITH HIV

Latest 2018 population size estimate suggests that 240,000 (230,000-260,000) PLWH currently live in Ukraine (UNAIDS, 2019). The national routine surveillance system reports that 136,849 PLWH have been enrolled for HIV care in medical facilities and 108,495 PLWH have been receiving ART as of the end of 2019 (PHC, 2019c, 2019d). Even such rough estimates provide us with the conclusion that less than half of PLWH (45% (41%-47%)) have started their ART treatment.

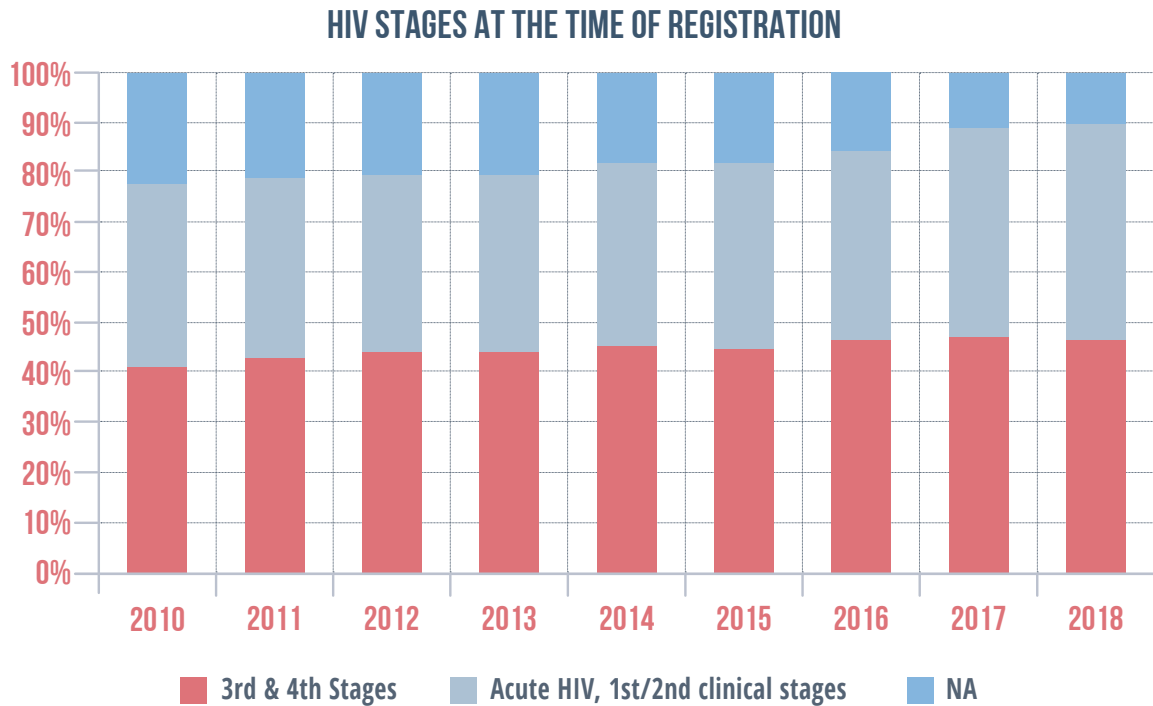
Analysis of HIV surveillance data in PEPFAR regions has been conducted using the HIV MIS 2010-2018 data. This analysis confirms that a substantial part of people newly diagnosed with HIV had advanced stages of the disease. Forty-one percent of all registered HIV cases in 2018 were considered as late CD4 presenters (<200 copies). Additionally, such tendency has only worsened within years, when in 2010 there were only 31% of late CD4 presenters among newly registered PLWH in PEPFAR regions. Multivariate logistic regression analysis showed that PLWH of older age, male sex, tested with any code, except assigned homosexual HIV transmission mode, were more likely to be late presenters in comparison with a group who were tested for HIV during pregnancy (**Table 2**).

Table 2. Correlates of CD4 late presentation among these who have been registered for HIV care in 2018 (ref.: 500+)

CORRELATES	AOR, 95% CI
Age (ref.: < 24 years)	
25-34 years	2.2 (1.5-3.1)
35-49 years	4.7 (3.3-6.7)
50+ years	7.9 (5.4-11.3)
Male sex (ref.: female)	1.2 (1.1-1.4)
Education (ref.: Complete higher education/bachelor)	
Childhood deprived of care	0.6 (0.2-1.6)
Primary/basic secondary	1.5 (1.3-1.8)
Complete secondary/vocational technical	1.4 (1.2-1.6)
HIV detection year (2010-2018)	1.1 (1.03-1.1)
Testing code (ref.: pregnant)	
HIV positive partner	1.6 (1.3-2.0)
IDU	1.6 (1.3-2.0)
Homosexual	0.5 (0.3-0.7)
Sexual risk	3.2 (2.5-3.9)
Other risk group	1.7 (1.2-2.5)
Children	0.5 (0.1-2.4)
Testing based on symptoms	4.9 (3.9-6.1)
Other	2.1 (1.1-1.4)

Another factor that can confirm a late presentation for HIV care is the HIV stage. **Picture 1** presents a stable trend and a sufficient amount of PLWH registered in care in the third and fourth stages (36-42% over years).

Picture 1. HIV stage at the time of registration for HIV care in 2010-2018.

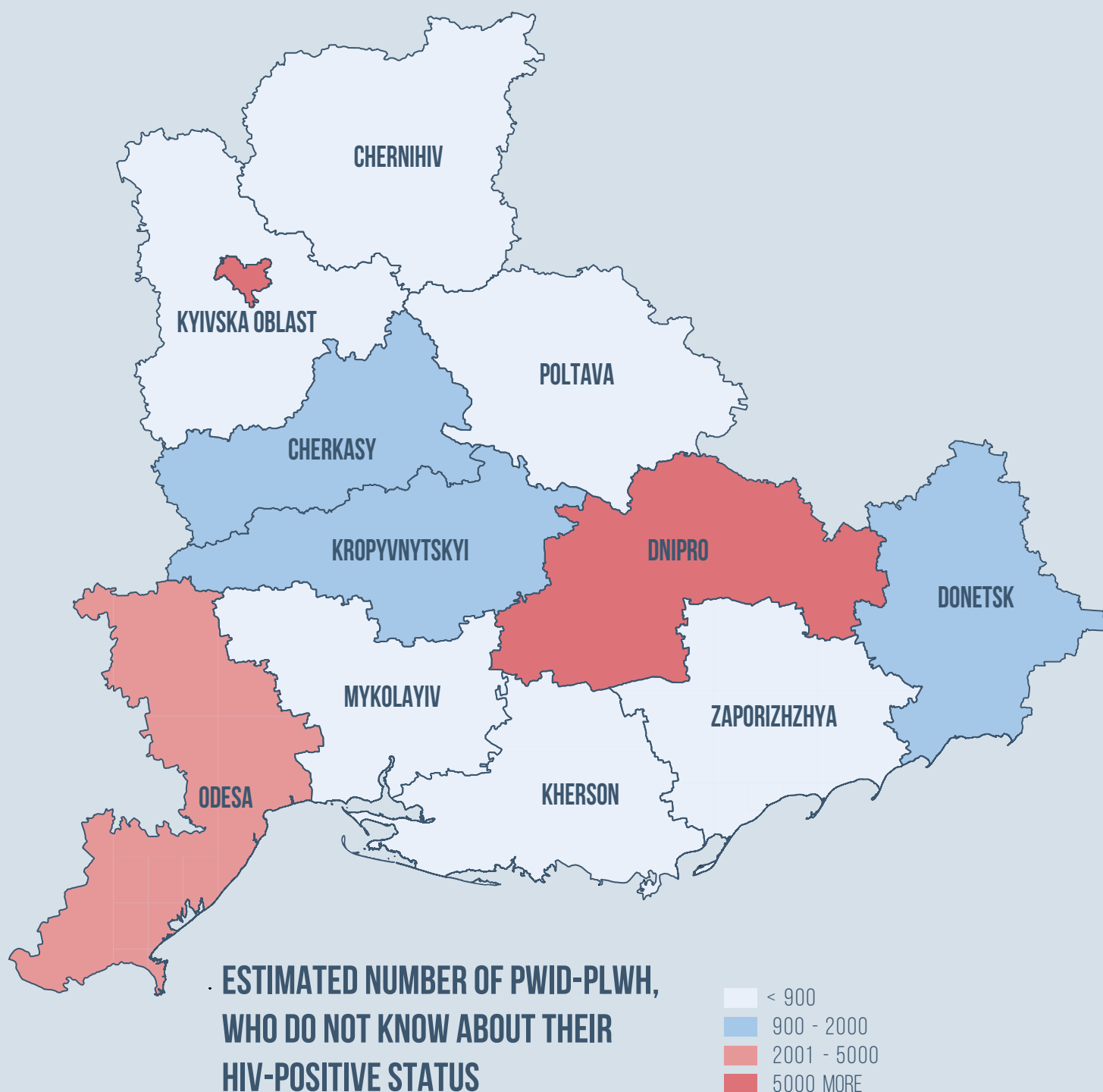


Such a brief analysis shows that a great amount of PLWH in Ukraine has sought HIV services after years of delay. The most at-risk groups such as PWID, MSM, and SWs play a key role in the HIV epidemic due to their vulnerability, behavioral practices and high level of stigma and discrimination towards these groups. However, to be effective in HIV case finding, it is not enough to focus only on at-risk populations itself. Prioritization of subgroups, defining the characteristics that can be the evidence of higher vulnerability within the key populations and among other groups should be done regularly. Socio-demographic characteristics will remain unchanged within programs, however, their recognition and acknowledgment of differences in service access across age, socioeconomic status, gender, geography, etc. might lead to a reduction of healthcare disparities (Smedley & Syme, 2003; World Health Organization & Commission on Social Determinants of Health, 2007).

PEOPLE WHO INJECT DRUGS (PWID)

From its onset, the HIV epidemic in Ukraine has been primarily concentrated among PWID population (Dumchev, Varetska, & Kuzin, 2017). It is estimated 223,500 PWID in PEPFAR regions of Ukraine and 13% (29,000) are unaware of their HIV positive status (Sazonova I & Salyuk, 2018; Sazonova, Duchenko, Kovtun, & Kuzin, 2019). Secondary analysis of 2017 IBBS data shows that these undiagnosed cases disproportionally distributed within regions. The largest amount of them concentrates in Dnipropetrovsk, Odesa, Cherkasy, Kropyvnytskyi regions and Kyiv city (*pic. 2*).

Picture 2. Estimated number of PWID-PLWH unaware about HIV-positive status in PEPFAR regions, 2017

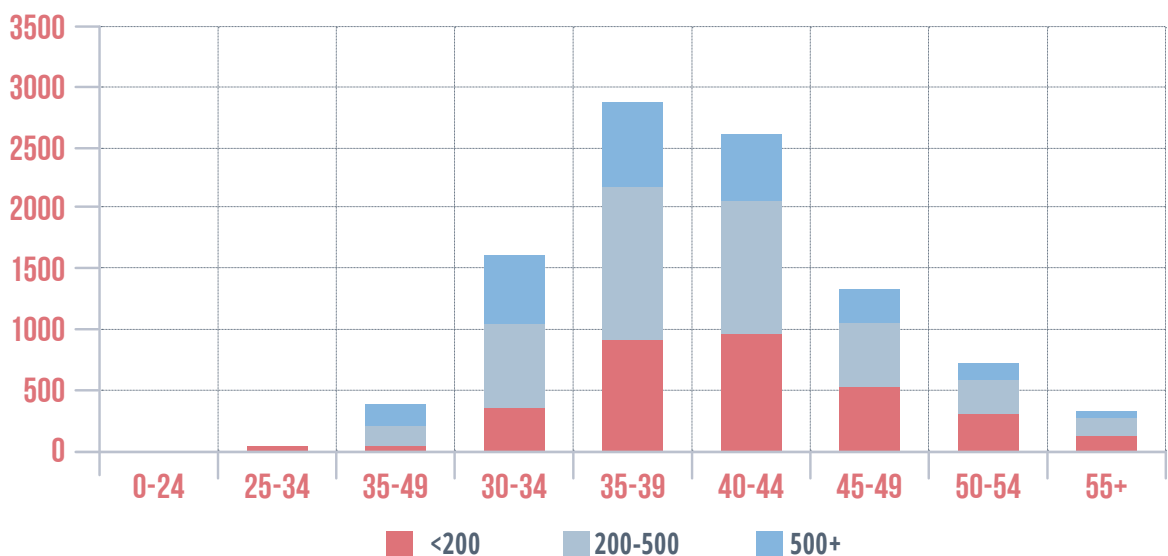


Results of multilevel logistic regression shows that PWID from older age groups (35+ years), with incarceration lifetime history, opioid users and those who practiced risky injection behavior were more likely to have undiagnosed HIV case. In contrast, male PWID, clients of harm reduction programs and patients of OAT programs were less likely to be undiagnosed with HIV (**Table 3**).

Table 3. Correlates of undiagnosed HIV-infection among PWID in 12 PEPFAR regions, 2017

CORRELATES	AOR, 95% CI
Gender male (<i>ref.: female</i>)	0.7 (0.5-0.9)
Age group 25-34 years (<i>ref.: <25 years</i>)	1.8 (1.1-3.1)
Age group 35-44 years (<i>ref.: <25 years</i>)	3.0 (1.8-5.2)
Age group 45+ years (<i>ref.: <25 years</i>)	2.8 (1.2-4.9)
Previous incarceration experience (<i>ref.: don't have such practice</i>)	1.5 (1.2-1.8)
Risky injection practices (<i>ref.: safe injection practices in the last 30 days</i>)	1.2 (1.01-1.5)
Injected poppy straw in the last 30 days (<i>ref.: no</i>)	1.6 (1.2-2.0)
Harm reduction client (<i>ref.: haven't used such services in the last 12 m.</i>)	0.5 (0.4-0.6)
Lifetime history of OAT (<i>ref.: no</i>)	0.5 (0.3-0.8)
PWID PSE in the city / 1000	1.03 (1.01-1.05)

Analysis of the HIV MIS data also confirms that 35-49 age groups have the highest proportion of CD4 late presenters among those who had been registered with IDU mode of HIV transmission (**Picture 3**).

Picture 3. CD4 results by age groups among patients registered for HIV care with IDU mode of HIV transmission, 2010-2018

Analysis of In-depth interviews with PLWH shows that injection drug use experience was present not only among self-identifiable PWID group. For example, some of the sexual partners of PWID that were recruited as a close social network of PWID have admitted IDU experience in the past, as well as adult men recruited as a group of CD4 late presenters. Triangulation of HIV surveillance data and findings from specially designed MOT study support such result and constitute that IDU mode of HIV transmission is underestimated and misclassified towards a heterosexual mode of HIV transmission in official routine HIV surveillance reporting system (Dumchev, Varetska, Kornilova, & Azarskova, 2017; Vitek et al., 2014). Such a tendency can result in poor needs assessment during case management and other support services.

Based on information from in-depth interviews with PWID we can determine three profiles: «PWID hanging out with friends», «A family person» and «A loner».

The first type of PWID is a popular person with many acquaintances and friends. These people use drugs and have broad social networks among current drug users. They spend almost all their time hanging around with their friends in the neighborhood, searching for some drugs or money for drugs. They also use alcohol at the streets, yards, and parks or near grocery stores. However, all these friends mostly support them only in leisure or drug-related activities. They can receive healthcare advice and psychological support only from their close relatives, e.g. mothers or sisters.

«Family persons» mostly describe themselves as transactional PWID to non-use stage, struggling to give up drug use. They are employed. They are also trying to give up their previous relationships with other PWID and to concentrate mostly on their families (wife and children) or former PWID. Some of them have previous HIV testing experience as clients of harm reduction programs.

«A loner» seems to be the hardest group to reach with HIV testing and treatment programs. They do not have any strong friendships or family relationships. They spend most of their time on their own. They have some support from family and friends but these interactions were not described as regular or permanent. These people have other major health problems, except HIV, e.g. TB, hepatitis C, hepatitis B, disability. Additionally, these people are rare visitors to medical facilities; they have no idea about harm reduction and HIV testing programs.

SOCIAL NETWORK OF PWID

There is a lack of information about the social network of PWID that may include sexual partners, other PWID, people who use non-injection drugs, friends, relatives, etc. In our study, we were focusing to explore two groups of PWID social networks due to their HIV vulnerability: (1) sexual partners and (2) friends who use non-injection drugs or non-regular injection drug users.

The most recent IBBS study among sexual partners of PWID has been conducted in 2015. This study has shown high HIV prevalence among this group – 15% (95% CI: 12.4-17.5), low awareness about HIV-positive status (33% among HIV positive), and large proportion of those who have previous IDU experience (23.5% (95% CI: 19.9-29.2) (Barska & Sazonova, 2016). Additional analysis of sex partners IBBS data merged with IBBS data of their PWID recruiters shows that HIV-positive PWID have 4.6 (95% CI: 3.0-7.1) times the odds to also have an HIV-positive sexual partner.

There are no representative studies in Ukraine about HIV prevalence among people who use non-injection drugs or are just friends of PWID. However, a secondary analysis of OCF program data (Smyrnov, 2015) provides us with promising results about HIV yield among these groups (**Table 4**).

Таблиця 4. HIV yield among friend/acquaintance/non-injection drug users recruited by HIV-positive PWID (2016 – May 2019)

YEARS	# RECRUITED SN	HIV POSITIVE RT RESULT	HIV POSITIVE NEWLY DIAGNOSED VERIFIED RESULT	HIV POS AMONG LTFU	HIV YIELD
2016	3208	721	119	69	3.7%
2017	7902	1831	307	429	3.9%
2018	5027	677	262	164	5.2%
5 months 2019	1636	259	81	47	5.0%
TOTAL	17 773	3488	769	709	4.3%

Based on information from in-depth interviews with SNs it is possible to identify three profiles: «A single mom», «A friend of PWID», «A woman in a relationship with PWID».

Single moms usually are middle-aged women, who care about their children, characterizing themselves as «a good mom». They have major support from their parents and relatives, have some permanent job and think that they «live a normal life». These women reported that they have no drug use experience; however, the majority have disclosed sexual relationships with PWID or PLWH in the past. Despite regular medical checkups, they do not have any HIV testing experience, except during their pregnancy.

Friends of PWID are represented by mostly single middle-aged men. Usually, they are hard drinkers and from time to time use drugs. They have a very huge network of different friends PWID and all other peers from their neighborhood. They have multiple sexual partners and some of them have incarceration experience. Some of them have a permanent job such as builder, tire fitting staff, railway worker, etc. They think that real support they can receive only from their mothers or other members of the family such as sister or brother. A few of them had previous HIV testing experience but in the majority, they usually avoid any medical services.

The last group is the current sexual partners of PWID. These people seem to be emotionally dependent on their partner and used to make any decisions only after the approval of their partner. Some of these partners have common children with PWID and think that they have

some support from their parents or other family members. Some of them have incarceration experience. In the majority, they avoid any medical services and addressing them only in a case of emergency. They also remember that they have the experience of receiving some harm reduction services with their partner or even HIV testing, but it was not a regular practice.

HIV POSITIVE FORMER PWID

There is a lack of data about former PWID in Ukraine. There is no data available about the size of this group, HIV prevalence, and behavioral patterns, or vulnerability profile. We partially can describe only two segments of this population: (1) patients of Opioid Agonist Treatment (OAT) and (2) rehab patients.

As of 01/01/2020, 11,385 people were patients of OAT in Ukraine. Among them 4,660 patients were diagnosed with HIV (41%) and 4,087 patients received ART (88% of HIV positive) (PHC, 2019b). We have evidence that some of OAT patients still use injection drugs; however, even among current PWID, OAT is a protective factor towards undiagnosed HIV (*see Table 3*).

It is impossible to define the number of rehab patients in Ukraine or even the exact number of rehab clinics itself. Based on expert calculations and projections, there are 300-500 rehab clinics in Ukraine (Osypyan A, 2019). According to the study results among rehab patients, 5.8% patients reported that they have HIV, 25.6% have or had hepatitis, 61% were sure in their HIV and hepatitis negative status, and 13% reported that they had never been tested either for HIV or hepatitis (Osypyan A, 2019).

Based on information from in-depth interviews with former PWID we can determine three profiles: «A religious person», «A harm reduction volunteer» and «A family man/woman».

The first group of former PWID became religious during their rehab program. These people still have some connection with rehab centers and visit a church. All of them were single and had broken any connection with PWID and their previous social surroundings. Only some of them have support from their parents or close relatives, the majority receives support only from church and other former PWID. Many of them reported that they have incarceration experience. Some of them received harm reduction services in the past and had HIV testing experience.

All harm reduction volunteers have experience of HIV testing and receiving harm reduction services. These people work at NGOs or help social workers as volunteers, they also can be known as gatekeepers of their neighborhoods for the provision of any outreach services. These people are current or former OAT patients. However, all of them have reported a very negative experience to receive medical services.

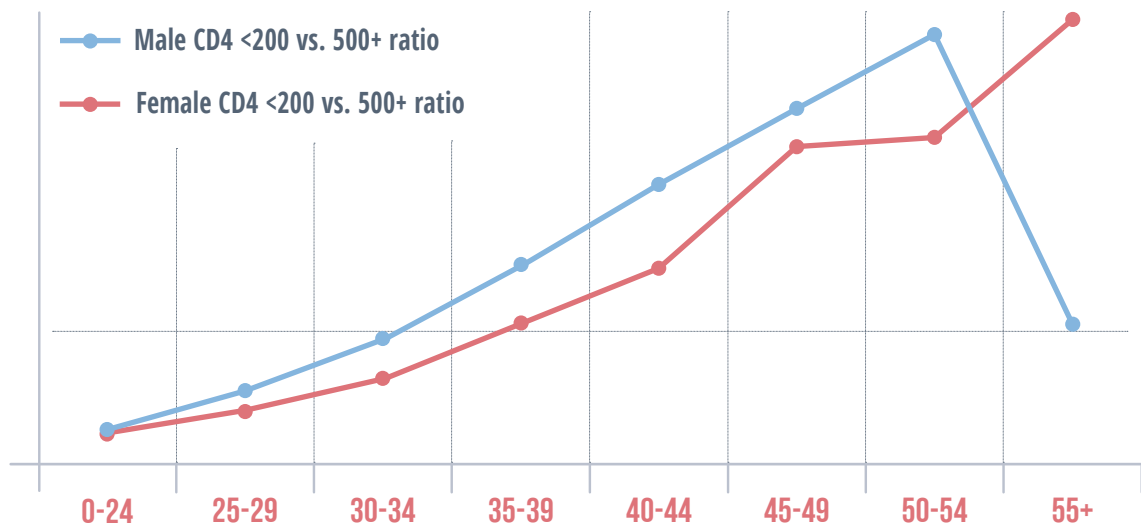
The last group is «a family man/woman». These people think that their family was the most important motivation to give up drug use and to stay «clean». These people have a husband or wife, some of them have children. They also reported that they have a permanent job (e.g. security, installation of air conditions, refrigerators, delivery, loader, etc.). These people told that they have pets (dogs or cats) and they see them as an important antistress factor helping them to stay «clean». Some of them have experience with harm reduction services in the past. They also have reviled highly negative experiences of medical services.

MALE PLWH AGED 35-55 YEARS WITH LOW CD4 LEVEL AT THE TIME OF HIV DIAGNOSIS

It is well established that men are less likely to engage in health-seeking behavior. They have a shorter life expectancy and more susceptible to illnesses (Hooper & Quallich, 2016; Kelly, Steiner, Mason, & Teasdale, 2019; Verbrugge, 1985). Several hypotheses try to explain such a difference. The first one called «an acquired risk» states that men might be engaged in riskier activities (e.g. riskier professions or hobbies) or more frequently practice risky behavior, (e.g. smoking, drugs, alcohol drinking). The next one is «psychological aspects of symptoms and cares» states that men have a lower level of sensitivity to body discomfort, they are less likely to associate their symptoms with illness, and they are also less likely to seek professional medical assistance. Besides, the last one is «prior healthcare», stating that women more actively seek medical care, visit doctors even with mild symptoms and more frequently are doing prevention medical checkups (Verbrugge, 1985).

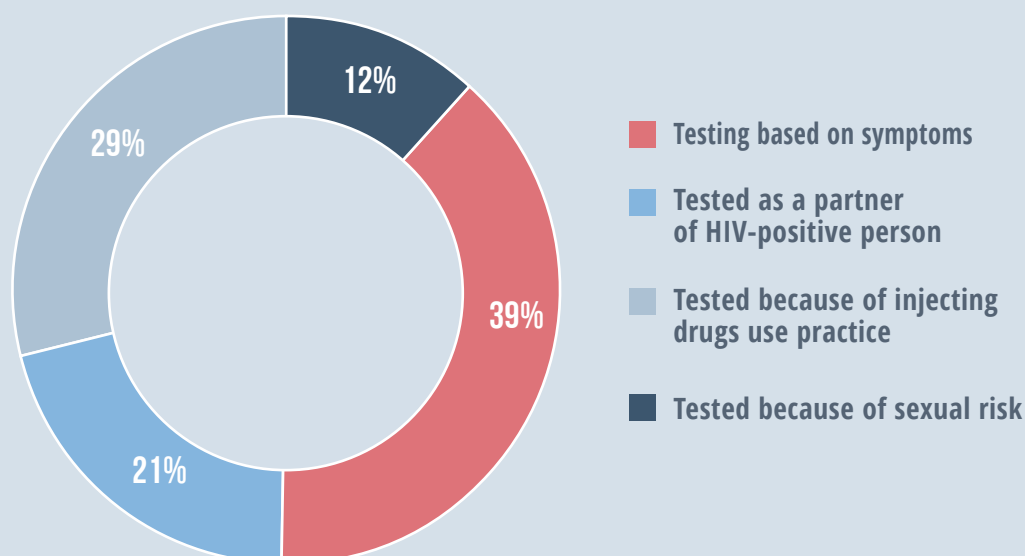
HIV data from Ukraine shows that the ratio of patients with low (<200) CD4 count vs. high (500+) count among men is greater than ratio among women for all ages, except 55+ years (*pic. 4*).

Picture 4. Male and Female ratios of CD4 late presenters (<200 CD4 cells) vs. patients with high CD4 level (500+ CD4 cells) at the time of HIV care enrollment, 2010-2018



The codes of HIV testing recorded in the HIV MIS have several limitations. Firstly, it is a subjective decision of a healthcare provider. Secondly, it contains an only primary condition, e.g. a person who has been tested because of sexual risk also can have HIV/AIDS symptoms, etc. However, even with these limitations testing because of symptoms among adult men with low CD4 level is the most common code (*pic. 5*)

Picture 5. Codes for HIV testing of adult men with low CD4 level, 2010-2018



Based on information from in-depth interviews with group of adult men CD4 late presenters we can conclude three profiles: «A single/loner», «A current/former PWID» and «A family man»:

The first group probably is the hardest group to reach with HIV testing. Single men who have major health problems, such as chronic diseases, disablement present this profile. These people have low self-esteem. They do not have friends or have just a few friends, also they have not had sexual partners for a long time. All support they are able to receive comes only from their mothers or grandmothers. These men have reported infrequent practice of receiving medical services, and they have no experience of HIV testing before their diagnosis.

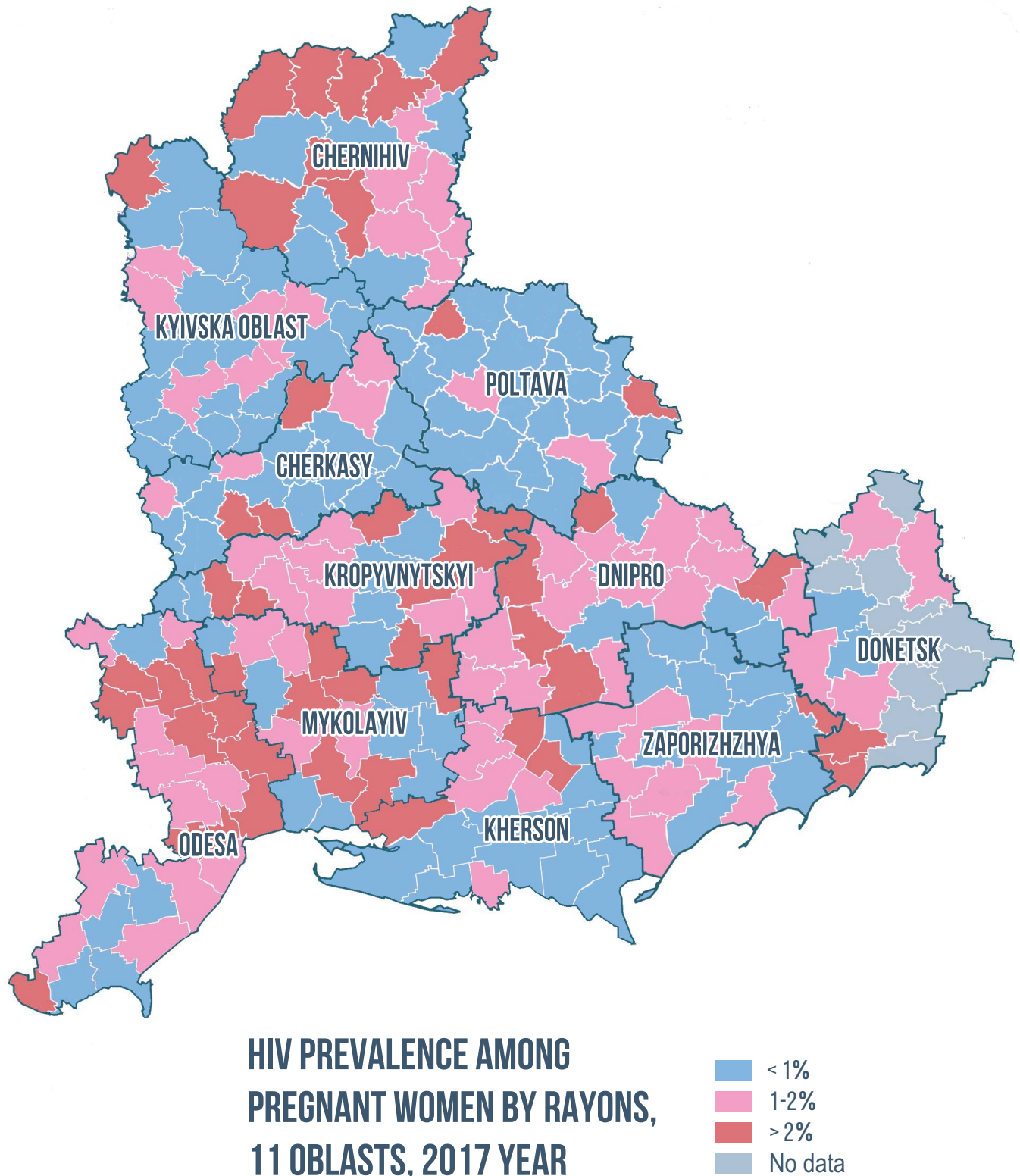
As it became obvious during interview, group of adult men with low CD4 level is also represented by people who use injection drugs or had such practice in the past. Some of them are current OAT patients. These men like hanging out with their friends, they can be seen at the neighborhood, near grocery stores, marketplaces, etc. They are spending most of their day looking for/using drugs, or drinking alcohol.

As the previous groups' profiles, adult men group represents «a family/married man» profile. These men are married and majority of them have children. Their wives support them in all decisions concerning their health. In addition, they perceive support from their mothers or close relatives. They have permanent job, e.g. builder, repair worker, railway worker, shop assistant, remote work in the Internet, driver, photograph, etc. It seems that they have active lifestyle; they have reported to engage in sports in the past or to have active hobbies. All of them reported to have a HIV-positive partner, however, there were cases when these partners were hiding their HIV status or had denied it for a long time.

FEMALE PLWH DIAGNOSED AT THE TIME OF PREGNANCY IN 2017-2019

During the last years, HIV-positive results among pregnant women in Ukraine were detected at 0.3% (PHC, 2019a). However, some districts have a much higher HIV detection level (*pic. 6*).

Picture 6. HIV detection among pregnant women in PEPFAR regions, 2017



Source: Center for Public Health of the Ministry of Health of Ukraine, 2017

CD4 level at the time of enrollment into HIV care is considerably high among pregnant women in comparison with other groups. The average CD4 in 2018 was 447 cells; only 16% of pregnant women had a CD4 level of less than 200 CD4 cells.

Results of in-depth interview analysis showed the following profile for women diagnosed with HIV during pregnancy. Most of them are married, have children or are still pregnant. They have a permanent job or are on maternity leave. None of the participants has reported about injection drug use experience, only one woman reported that her husband had such practice in the past. Most women knew that their husbands or a previous sexual partner were HIV-positive, but some women had no idea how they became HIV-infected. These women reported regular medical checkups and health-seeking behavior. They have support from their husband and family and they have initiated ART treatment as far as they became aware of their status. All these women had no HIV testing experience before pregnancy.

PLWH DIAGNOSED WITHIN PROVIDER INITIATED TESTING IN MEDICAL FACILITIES (PITC)

For the in-depth interviews, we have recruited two types of patients diagnosed within provider-initiated testing in medical facilities: these who have received access to HIV care at the early HIV stage and these who were diagnosed with advanced cases.

Middle-aged men and women present the first group. They have a permanent job (men: factory worker, shop assistant, builder; women: assistant, pharmacy, shop assistant). They are married and have children. Men and women aged 50 or older represent the second group. Mostly they reside in rural areas. They are divorced or widowed and have adult children who live separately from them. They have poor health that became a reason to address medical facilities (e.g. TB). They have never or very seldom addressed medical facilities. They have no information about HIV and have no idea that they might be infected. They have advanced stages of HIV / low CD4 level, have other opportunistic infections and their children or friends insisted that they visit a healthcare facility this time.

WHY PEOPLE DO NOT SEEK HIV TESTING WHEN IT IS AVAILABLE?

HIV testing in Ukraine is a widely available service. HIV testing sites include primary and specialized medical health facilities, non-governmental organizations that provide services to the key populations, etc. (PHC, 2018). However, it is estimated that approximately 40% of PLWH are still unaware of their HIV status or were lost to follow-up for HIV care and treatment. Several theories can explain the health-seeking behavior and behavioral factors of treatment adherence.

One of them is Health Belief Model (HBM) that was developed in the 1950s and was improved over time to explain people's failure to participate in programs, to prevent and detect diseases (Hochbaum G. M., 1958; Rosenstock, 1960). It suggests five constructs that can influence a person's behavior to seek healthcare: perceived susceptibility, perceived severity, perceived barriers, cause to action and self-efficacy. The basic principle of the model is that people engage when they believe that such actions can reduce harm and will involve positive consequences. The results of in-depth interviews show that there are several major problems for getting people to HIV testing.

The first one is attributed to challenges in perceived susceptibility to HIV, which can describe the behavior of women who were diagnosed only at the time of their pregnancy, some of the adult men group, some PITC patients and social network of PWID. These people usually lack information about HIV and have never perceived the threat of being HIV-infected personally. Such an attitude is true not only for patients itself but physicians from primary healthcare facilities. Many representatives of these groups reported that they had regular medical checkups, always appointed healthcare with illnesses and prevention measures, however, they have never been suggested with HIV testing in the past. In addition, interviews with adult men CD4 late presenters group also reveals that they had received systematically wrong diagnosis and treatment that were dealing with their symptoms and HIV testing was the last option that was offered to them only when all other measures were not effective

“ *I did not pay attention, because somehow I was not interested. I did not even pay attention to it. I knew what HIV was, but I thought that it was not about me.* ”

(Adult man CD4 late presenter, Mykolayiv)

“ *I never refused (HIV testing), because before that no one had offered. I had never HIV test before I felt really sick* ”

(PITC patient, Mykolayiv)

“ *... such questions have never arisen. Maybe only in 2017-2018, I heard there once, or twice... Well, I thought that this was not about me and I had never thought that I could be infected...* ”

(Former PWID, Dnipro)

“ *They failed to cure me last time, I got the wrong diagnosis. Well ... they did not test me right away. I just was prescribed with a lot of antibiotics.* ”

(Adult man CD4 late presenter, Dnipro)

“ *... at my local hospital, no one suggested to test me. Well, for 2 weeks I was not treated the appropriate way. ... Well, just in such small towns, in rural areas, there is much less talk about this situation, about HIV.* ”

(Adult man CD4 late presenter, Dnipro)

“ *I was in the hospital, was treated for pneumonia. Well, they prescribed me pills. That's it. Then I was not cured, I stayed in the hospital during a month.* ”

(Adult man CD4 late presenter, Zaporizhzya)

Attitude to their health and perceived severity of any diseases including HIV can be very low for some representatives among the PWID group, former PWID, social network of PWID and among PITC group. There are examples when even in case of real health emergency these representatives decided to rather run from medical doctors and hospitals. Considering that HIV-infection can be asymptomatic for many years, extra efforts should be done to convince such people to use medical services; benefits should be articulated very clearly.

“ Well, about my health ... in principle, I'm such a person that I somehow don't care about my health. I do not know why. Well, that is, I can ... there was a situation, right? I can even tell. I got a sick tooth, I arrived, they started to treat, put a temporary filling, put it there ... I do not know what they put there, some antiseptic, and they said to come in 2 weeks, but not later... Ultimately, I spent like a year and a half with this temporary tooth filling. Again, it got sick again after 1.5 years. I went to the dentist, they opened it again, they said, «why didn't you come, and on top of that, you have cotton wool here.» That is, the doctors were shocked. Ultimately, like that, I have lost a tooth. In addition, I will even say more, I have not lost it, I still have it, but I need to pull it out. Nevertheless, I do not feel like pulling it out, and somehow I still have it.

(SNs, Kyiv)

“ Well, let's take 2016, the last one, yes? The last thing I remember is very bright. I lost 25 kilograms. Well, of course, not in a day or two. Well ... let's say since the fall and here was winter... I could not even get up and go to the toilet... I refused to go to the doctors; I did not believe them. Although I ... was 99 percent sure that I had HIV because my husband was HIV-infected. ... And no one ... Even my mother was not able to force me to go to the hospital...

(Former PWID, Odesa)

“ I did an injection in my inguinal vein, and I brought an infection there, I didn't get into a vein. An abscess began to appear there. But since I was in use I was told that I didn't need an ambulance, doctors. I had a temperature of over 40. And that's all anyway, I got up in the morning, ran for my dose... The next day I had a higher temperature. There was even case when an ambulance came to me. They told me that I need urgent hospitalization. I went out with them down the street, but run away from them, I was jumping on one leg ...

(Former PWID, Kyiv)

“ P: «I haven't addressed any hospital... My leg is broken, my arm is broken here.»

I: «Have you seen your doctor because of broken arm and leg?»

P: No. My daughter had bandaged it up ...

P: I was in the hospital - yes, three times, when I gave birth for the first time... And when I had son, I gave a birth to my son at home.

(PITC patient, Odesa)

The next group is very similar to the previous one: people who decided to make a profit from HIV testing programs participation and refuse from HIV treatment. Several programs in Ukraine offer monetary compensations for participation and HIV testing. Some cases were reported when people (mostly among PWID) chose to refuse from treatment to be able to participate in such programs once again, e.g. by changing testing sites or visiting several projects in their city or in a neighboring one. Some of these people refuse from HIV care and treatment just because they are afraid to be hospitalized because they thought that they would not be able to use drugs for a while or continue their usual activities.

“ *I know one or two people who have come there 3-4 times because of money. They have HIV status, but they do not take ART. I tell them are you ok? You are going to die. You are using drugs.... you are not eating for days. You are not sleeping... And you do all these things only because of money. ... There are several programs in the city. They are coming from one to another to get money and to show their HIV. They do this for weeks; they take a money and refuse from treatment. The point is not to get money, but to be treated somehow, to do something about it.* ”

(Former PWID, Kyiv)

The next group is attributed to perceived barriers and reports negative experience of receiving medical care. This category may include own experience or stories from other people about stigma and discrimination towards PLWH, PWID, alcohol users or other vulnerable groups, time-consuming process to get medical consultations and treatment, service charges, direct or indirect HIV status disclosure (which is especially concerning in small cities and rural areas), absence of IDs or other documents.

“ *You tell them about the HIV status, and they run away from you. And when I was with a child in the maternity hospital, they have behaved as if my children also were infected. Well, I do not know why they have treated us so badly ... because either we are poor, or I don't know...* ”

(PWID, Zaporizhzhia)

“ *I was hospitalized after an accident, after an accident with a stomach; they came up to me in respirators and gloves, as if I were some kind of outcast...* ”

(SNs, Zaporizhzhya)

“ *... if you are some kind of alcohol or drug addict ... they look arrogantly at you or something like that...* ”

(SNs, Kyiv)

“ Well, if there is no money, and you are sick, then there is no point to go. You will sit in the hospital, which is opened until noon, even if you have arrived at 8 o'clock and taken a queue. He (doctor) has appointments until 11, after that he turns around and leaves. And that's it. Then he goes somewhere to the department, says if you want you can go, but it will be for payment... ”

(Adult man CD4 late presenter, Kyiv)

“ Now I'm afraid that if I have such a diagnosis, then everybody will know ... The city is small ... I don't know. I understand that I should not to tell everyone this; it is confidential. But I do not trust my doctor, because I have heard about her not very good things ”

(SNs, Dnipro)

“ Of course, not all doctors act like this, but what I cannot understand is the situation when a doctor is trying so hard to get something from you ... It's clear that they have low salaries, we all want more ... And I'm not the only one, unfortunately. You come with one problem, they will make up another one, and the second, and the fifth. You go out with nothing because you have not been provided with a service, and it is not clear what to do next ... ”

(SNs, Odesa)

Another group that finds HIV testing as a challenging process is those who prefer not to know about HIV-status rather than go and test. Fear to know their HIV status are very common barrier and it was reported by representatives of all studied groups. Again, here we have problem with myths about HIV that still spread in the society, high level of stigma towards PLWH, lack of information about treatment and «U=U concept».

“ Yes, the simple thing when you don't know at all ... you live without this knowledge because I believe that faith and knowledge work. ”

(Former PWID, Zaporizhzhya)

“ By the way... when I was hospitalized because of my hand, then they offered the HIV test to me. But at that moment I have refused. Because ... well, firstly, I was not ready to do this. Secondly, I was afraid to know about my status ”

(SNs, Kyiv)

“ This is a closed topic for discussion. All the boys and girls who have sex, but who do not have a regular partner, all of them are afraid of this test. I was very afraid as well ... I was even afraid to watch ads on TV. ”

(Adult man CD4 late presenter, Dnipro)

STRESS, STIGMA AND FEAR TO KNOW HIV STATUS

Fear-based campaigns have been widely used by public health specialists for decades, and in the case of smoking, these campaigns have proved its effectiveness. From its onset, HIV/AIDS campaign had started to use fear-based messages to prevent HIV risk behavior. Such messages were very popular in the early years of HIV-epidemic; however, it was highly criticized by the community as such that inherit stigma (Fairchild et al., 2018).

Ukrainian HIV/AIDS-related messaging had used a fear-based approach in massive campaigns at the end of the 90s – beginning of 2000s with forming a general opinion to perceive HIV/AIDS as a “plague of 20th/21th century”. Still, such messages can be easily seen on different web-resources and used as a topic for optional class hours among school and college students (Baydanchyk A. V., 2018; Study Department Yavorivsk District Council, 2019).

The most prevalent request from our qualitative study participants was to change HIV/AIDS-related messaging strategy, to include information that can help to reduce fear in the society and to stop spreading information about HIV/AIDS as a deadly disease. In contrast, such information as the efficacy of antiretroviral treatment, “undetectable equals untransmutable” strategy, availability of ART drugs with minimal side effects, free of charge medicine and most of the treatment services, etc. have not reached general and target audience in the major scale. Participants revealed that they were able to receive this information only when they got to the AIDS clinic or NGOs. All other test providers from primary healthcare, in general, failed to provide comprehensive information about HIV and treatment to reduce their fears and stigma.

“ *No, I had a rapid test. They only collected the blood and that’s it... They haven’t told anything. I went to Kherson to the hospital, I was hospitalized and they gave me something, some pills, I don’t know, because no one said anything* ”

(SNs, Odesa)

“ *To be honest, no, he did not recommend me anything. Because it was diagnosed in a hospital by regular doctors and he knew nothing about HIV infection* ”

(Former PWID, Kyiv)

“ *She (physician) said, oh, it (HIV test) must be some kind of defective one... Her hands were shaking... And then she said, there is a strip (on the test indicator), go to the infectious disease doctor... If my mother was not with me at that moment, I wouldn’t go further. Honestly. Mom just led me by the hand. And that doctor staid in shock...* ”

(SNs, Dnipro)

“ *It seems that now it was told everywhere that this disease is not so scary... and it is not embarrassing to know your status. But for some reason, we have our doctors who should understand and know even more about this disease, but for some reason they are afraid, look at you like a leper. I don't understand this...* ”

(SNs, Kyiv)

“ *We need to inform healthy people that you can't turn away from such people. They are afraid of them (PLWH), insult them... Our people do not understand this disease as it should be. They consider it like a plague, so ... Not even a sick person... He may be sick, but he is afraid of a healthy one. Healthy people can do more harm than sick one...* ”

(Adult man CD4 late presenter, Mykolayiv)

As a consequence of all this, some participants told about their delays in deciding to get HIV tests due to fear to know the HIV-positive status and they had chosen strategy “better not to know” for many years. They also told that they were lacking information that diagnosis of HIV on early stages can simplify HIV treatment and shorten the path to get back to the “normal life”. When they finally got to HIV testing and received their HIV-positive results it was a highly stressful situation for them.

Most of them had desperate feelings and desire to run away, some had plunged in a deep depression. Some participants told that they had experienced such condition for several days or even weeks. That makes delays or even refuse from HIV care and treatment.

“ *I went, went out, immediately drank a bottle of vodka, ... I had depression... I woke up, I did not believe, I was strolling around for a week and trying to get rid of these thoughts.* ”

(SNs, Zaporizhzhya)

“ *You know, when I left, I was in tears. It seems to me that the doctor should talk to me, to calm down me somehow. Well, maybe not calm down, but to support... Nobody supported me.* ”

(Woman diagnosed during pregnancy, Mykolayiv)

Another frequently described form of dealing with getting HIV-positive is denying. Refusing to acknowledge that something is wrong is one of the ways of stress coping that can lead to anxiety and depression. People were talking of getting HIV positive result of a screening test or even confirmative one but decided not to take any further actions, refuse from case-management services and treatment.

“ They didn't take me to the center (AIDS center). Naturally, as for any other person, my first reaction was a denial of the disease, of the diagnosis. This is the first reaction for any person. Also, the people I know and who were HIV infected ... They are no longer alive... They were too ... their first reaction was denial. This disease does not exist, it does not exist. This was all invented for the sake of budget money. I don't know where this information comes from, I won't say it. That is, the first is denial. Also, my first was a denial. I was waiting for about a year. I had a not very healthy lifestyle, drunk alcohol... Had a very active sexual lifestyle along with alcohol consumption ”

(Former PWID, Mykolayiv)

“ At that day and after, I have not visited them for syringes, I was scared, ashamed. I didn't want to ... they were like a reminder to me... ”

(PWID, Kyiv)

However, not only HIV related stress may create barriers to access HIV treatment. Any other personal circumstances may lead to delay with ART

“ The last time, before I found out that I had HIV, my husband died. (...) But I had two children, it complicated the situation somehow ... there was no time to relax, no time to visit hospitals. You just should work hard. ”

(Woman diagnosed during pregnancy, Dnipro)

PLWH who doesn't care about their health is one of the hardest groups to enroll in HIV care. Especially in the situation when HIV has an asymptomatic stage for many years and does not bring discomfort for its host.

“ My reaction was ... whatever. I was in such crazy (drug) use that, frankly, I did not care. If I have it (HIV), or not ... I have not even been in a shock, to be honest... ”

(Former PWID, Kyiv)

It is important to understand how a person who has the disease or just at-risk to HIV addresses or manages stress. It can be done individually or with help of family, friends, relatives of health providers, but it might have a major influence on health outcomes, in our case, on a decision to get HIV test and management of further steps for adherent HIV treatment.

SOCIAL NETWORK ROLE

An acknowledgment of the nature and types of relationships, types of support and role of the patient network in making health decisions is one of an essential component to guide efficient programs. There is a relatively large portion of literature that describes HIV transmission dynamics through social network (Friedman et al., 2018; Pines et al., 2016; Shushtari et al., 2018; Verdery, Siripong, & Pence, 2017). Some published literature also provides evidence that the social support role of social networks is a key element to improve HIV care continuum outcomes (Brennan-Ing, Seidel, & Karpiak, 2017; Ghosh et al., 2017). Using the results of the qualitative study we will try to explore the nature of relationship and support in HIV related health decisions.

SOCIAL SUPPORT

It is well-established, that social support has a positive association with health outcomes. Epidemiological studies also suggest distinguishing received and perceived social support, which is presented just by perceived availability of different types of support (emotional, informational, financial, tangible, etc.). Furthermore, perceived support is associated with positive mental and physical health outcomes (Herrero & Gracia, 2007; Uchino, 2009).

Study participants have identified several people who play an important role in their life and provide support. They also shared an opinion that they can disclose HIV-positive status to these people because they perceive their relationships as trustful and faithful.

Family plays a key role in almost all study participants. Most of male PLWH said that they can receive any support from their mother, they share information about HIV status and receive help to manage their treatment, and they have care and support. Married participants described the same relationships with their wives. Relationships with their father entail more diverse opinions. Most participants reveal that their fathers supported them almost as much as their mothers do, but some PLWH, especially among PWID group, do not maintain any relationship with their fathers. Other relatives such as sisters or brothers also were described as an example of support. However, some participants have decided to hide their HIV status from them. Nevertheless, even in such cases, they think that they can rely on their sisters/brothers in any situation. Relationships with other relatives were described with lower level of reliance. A few participants have a trustful and close relationship with their grandmother, uncles, etc.

Group of former sexual partners and their relationship with PLWH was subject of discussion during interviews primarily for the purpose to explore the possibility to get these partners into HIV testing. Only a few participants said that they were ready to speak with their sexual partners about HIV. Other participants do not maintain relationships with such partners and do not agree to provide their contacts to medical workers. The situation can be complicated also due to HIV infection duration. The majority of PLWH were diagnosed with advanced stages that add substantial challenges to identify past sexual partners and to reach them.

Friends or other acquaintances also were described in the group who care and is ready to provide support. However, not everyone was ready to talk about HIV status with his or her friends. Among the PWID group, HIV status disclosure also was a problematic issue because they did not want to be stigmatized by others, to become group outcasts or to be punished if someone else from the network gets HIV-positive status. Nevertheless, there were also stories when after getting of HIV positive status, PWID had disclosed it and were trying to motivate other group members to be tested. Some PWID decided to choose tactics not to tell about HIV status but still motivate others to get HIV test justifying everything with PWID risk-related behavior.

Group of colleagues, and sometimes neighbors, also plays some role and provide support to PLWH. PLWH do not disclose their HIV status to these people, however, these people are perceived as close surroundings to spend time with, to have some conversations and share common interests, etc.

Still, there is a group of people among PWID, former PWID, adult men - CD4 late presenters and PITC group that have identified themselves as lonely people who have no support and do not maintain any important relationships.

RISK NETWORK

Social network influence and observational learning are key elements for making health-related decisions. Person decision to make any actions based on observations of someone else behavior and the consequences of this behavior, especially if this person is an important member in the network (Bandura A., 1986). Conversely, observing that someone experiences a negative outcome of certain behavior can decrease the likelihood to perform the same actions in the future. This theory can explain a negative attitude and distrust toward healthcare and medical workers. Even in case when some participants did not have personal negative experience they rely on someone else experience and perceive this as a piece of personal knowledge.

There are examples of refusals from HIV testing, HIV treatment, spreading myths about HIV or alternative methods of treatment among different types of community, especially among PWID or their close network.

“ They say, «I can't go there, because my liver is bad»... And to be able to receive a therapy, they need to be hospitalized first. But they cannot do this, because there are no drugs at the hospital. And so they just die, that's all. They go and say: «let it be so».

(Former PWID, Kyiv)

“ Well, I have communicated with such people who do not want to go here and to start therapy. Because they just do not believe in all of this. As I did as well. We had a group that did not believe in all of this. And we had denied it (HIV) as well

(Former PWID, Mykolayiv)

“ After she has received a confirmation of her HIV-positive status, she told me that she already had an HIV test 3 years ago in another city and her HIV result were positive. But she had refused to believe and left the health facility...”

(Adult man CD4 late presenter, Zaporizhzhya)

“ He does not believe; he does not believe that HIV exists at all. ... He explains this by the fact that this is just some immunodeficiency disease. But it is not such a terrible one (as HIV) ”

(Adult man CD4 late presenter, Mykolayiv)

“ And then I heard negative reviews. People who were on therapy had a very negative opinion; they felt bad and had some side effects. A bunch of such factors ... they said that it was possible to live without it (treatment) and everything would be fine. ”

(Woman diagnosed during pregnancy, Kyiv)

However, some negative experiences of friends, spouses or relatives after ART refuse can lead to the opposite outcome, when a person starts to understand that ART treatment is only one method to stay healthy. Such people also try to spread this information and change the mind of other people who still deny ART.

“ Some people have taken my advice and they are using ART now. But some others had begun treatment and stopped. The reason I do not know... But the result is visible. Those who are still using ART treatment, they feel great, like me. And those who stopped, they feel very bad. Dying. ”

(Adult man CD4 late presenter, Kyiv)

“ And then, of course, you understand that after the death of your husband ... who also did not believe it until he was gone ... I realized that everything is here, you just need to take therapy, have a healthy lifestyle, and everything will be fine ”

(Woman diagnosed during pregnancy, Dnipro)

PROVIDER-PATIENT COMMUNICATION

A great bunch of research about provider-patient communication suggests its importance for reaching positive health outcomes. It plays a key role in making the right decision about diagnosis and treatment, forming treatment adherence, especially for long-term treatment regimens (Street, 2013; WHO, 2003). The most effective communication responds to emotions and at the same time provides clear task-driven guidelines to enable patient self-management. To build a trustful relationship, it is important for physicians to be informative, respectful, supportive, nonjudgmental, sensitive and to express interest to patient's views (Deledda, Moretti, Rimondini, & Zimmermann, 2013; Gordon, Street, Sharf, & Soucek, 2006).

During in-depth interviews with PLWH, we have discussed practice of HIV diagnosis and further medical care.

MEDICAL SETTINGS TESTING

There were diverse practices of HIV testing within medical settings. The first one presents HIV testing based on the symptoms when all other treatment options were failed to cure the patient. Such examples also usually accompany late HIV diagnosis and advanced HIV stages. Very few examples explore the situation when HIV testing was offered by medical workers to screen HIV status without any medical symptoms.

“ *I was not treated for the last time, I got wrong diagnosis. Well ... they didn't test me right away. I just was signed with a lot of antibiotics.* ”
(Adult man CD4 late presenter, Dnipro)

“ *... at my local hospital, no one suggested to test me. Well for 2 weeks I was not treated how it was appropriate. ... Well, just in such small towns, in rural areas, there is much less talk about this situation, about HIV. And I think it's a lot more «run-down» than in the cities.* ”
(Adult man CD4 late presenter, Dnipro)

“ *I was in the hospital, I was treated for pneumonia. Well, they prescribed me pills. That's it. Then I was treated, I was in the hospital for a month.* ”
(Adult man CD4 late presenter, Zaporizhzya)

Testing during pregnancy is highly recommended and covers almost the entire target population. In the majority of described situations, women did not expect to receive HIV positive results, had never sought HIV testing before pregnancy, as well as they had never been offered an HIV test before pregnancy. However, there were a few stories when women had no HIV testing before pregnancy even in a situation when they were aware about HIV-positive status of their sexual partners.

“ *Well, you know, I can only say one thing. If I were not pregnant at that moment, I would not have known that I was infected.* ”
(Woman diagnosed during pregnancy, Dnipro)

“ *This was not my initiative, I was registered in the antenatal clinic because of pregnancy and this was a mandatory analysis.* ”
(Woman diagnosed during pregnancy, Zaporizhzhia)

Personal motivation to have HIV testing for people who do not identify themselves as risk groups is a very rare phenomenon. The majority do not have information about HIV, testing sites and availability of treatment. They do not visit medical facilities requesting HIV testing or counseling services; but they can get an HIV test, for example, in case of medical referral before surgery.

“ *... only when I had gynecology problem. I had started addressing these state hospitals to find out what it was. And they said that I need surgery, and before it, I had to do diagnostic tests ... and HIV test was one of them* ”
(PITC, Mykolayiv)

Poor HIV counseling is one of the commonalities that combines the majority of events when HIV was diagnosed within primary healthcare. There were situations when physicians were nervous and afraid to report HIV-positive diagnosis, had provided very limited information about HIV and had rely just on referral to AIDS clinics where patients would be able to receive specific information.

However, all participants expressed that AIDS clinic specialists provided them with comprehensive information, high quality of HIV counseling, support and a friendly attitude. Only at this stage, they understood that they would be able to live a normal life while using ART treatment.

One more group has described their experience of HIV testing in specialized medical facilities such as AIDS, STI and TB clinics. In this case, they were targeted with HIV testing because of other disease such as TB, hepatitis or STIs. HIV counseling at these facilities was evaluated as informative one, and referral to HIV treatment was done almost without any delays.

Most of the PLWH choose a medical worker as the most reliable person to receive information about HIV and treatment strategies. They reveal that they trust the information that comes from a medical worker, believe that such information is the most reliable and can motivate them for HIV testing and treatment. However, they have hardly received such information from medical workers before HIV diagnosis. The majority of participants who addressed medical care before HIV diagnosis had conversations only about current symptoms and complaints.

OPTIMIZED CASE FINDING AND NGOS SETTING TESTING

Optimized case finding (OCF) and other NGO strategies of HIV testing are available for key populations and their social and risk networks. Participants with experience of such services have described friendly attitude, peer-to-peer consultations that help them feel comfortable, remove barriers and eliminate any stigma.

“ *I was shocked! ... In a good sense of this word. Everything was free, and you can come once a week, if necessary. They recorded you as a client; you do not pay any money.* ”
(Former PWID, Odesa)

“ *Firstly, you can take everything for free. ... I do not say that I have no money for syringes, but why to spend money if the guys give you everything for free. And you know that you can come even if you need advice, you can ask someone there, you can always ask them and talk with them, because they are the same as you. They are the same! Therefore, you know that no one will hand you over to the police...* ”
(Former PWID, Zaporizhzhya)

OCF testing has an additional advantage while providing monetary incentives for HIV testing and the recruitment of other peers. Groups of PWID and their social network see this advantage as one of the key elements that can motivate them or their friends to have HIV testing. However, some representatives observe an opposite effect when monetary incentives became top priority instead of health issues. There are some examples when such people were searching for different projects to get money and refusing to start treatment or register in care.

“ *It is good. So many, so many people came for testing due to this coupons and money...* ”
(SNs, Kyiv)

“ *In fact, as for me, this is a very interesting program. ... As for me, for them (PWID) 70 hryvnias is one-time to come ... at least there is money for some dose or a pack of cigarettes. ... I was once given a coupon and I came for testing. The test showed that I was positive. But to be honest, I had already known that I had HIV infection. But still, I went to make money. They also gave me three coupons, and I told my acquaintances ...*

”
(PWID, Kyiv)

CASE MANAGEMENT

Case management was highly evaluated by all participants who had received such services in the NGOs CITI project or at the Care & Support project. PLWH were strongly satisfied with these services and communication with their case managers. They were surprised to have a person who cares about them, can help to start treatment, go through all testing procedures and other medical diagnostics that were needed to initiate ART. These specialists provided detailed and comprehensive information about HIV, explained procedures of ART treatment and its effectiveness, and provided psychological support. They were available almost 24/7.

“ *When I had received a positive result, ... by the way, I'm very ... very grateful to those guys who went with me to the hospital. And along the way, we were talking a lot. He told me all these things, that you can live with it (HIV-positive status), that there was nothing to worry about. ... He also accompanied me everywhere in the hospital. Well, there was some support, there was support, well, thanks...*

”
(PWID, Kyiv)

“ *She went to all the doctors with me. ... she also played a role. For example, I had an appointment for a blood test. I woke up in the morning with thoughts that «I don't want to go». But she was waiting for me, and because of it, I was not able to refuse. ... Then again, I agreed with her, she was waiting for me again. If she wasn't waiting, I probably would refuse to go, as it was many times before...*

”
(Former PWID, Odesa)

“ *Although, again, the social worker ... thanks to the social worker, he helped me. I have received psychological support from him. Thanks to him ... I am grateful to him. He was always with me until I was registered and started treatment. Well, he spent almost 2 days with me, visited all the doctors until they prescribed me the treatment ... well, I still have contact with him and can ask about advice...*

”
(Adult man CD4 late presenter, Kyiv)

INDEX TESTING POTENTIAL

Index testing is highly recommended as an effective strategy to improve HIV yield by targeting sexual and injecting partners of HIV-positive people. Some examples of this strategy implementation have demonstrated HIV yield up to 20-40% (Jubilee et al., 2019; Khongonyowa L, Schouten E, & Abdallah A, 2018; Opollo et al., 2018; Shamu et al., 2019). One of the most important parts of such a strategy are the solicitation of the index case contact information and approaching them for HIV testing.

Our study participants have no experience with such a project. However, we are still asking questions about their readiness to share contact information or inform and recruit their partners themselves. As a result, almost all participants who were married reported that they have already disclosed their HIV-status to their spouse and she/he had HIV test.

The idea to approach other sexual partners was rejected by most of the participants for several reasons: they did not maintain relationships with them and had no contact details of them, or they did not want to put themselves at risk that their HIV status can be disclosed.

Other people that were recruited for HIV testing by PLWH were parents, children, and other family members. All these categories are less likely to have HIV because they probably did not have sexual or injection contacts. Even children can be assigned to the group with a low probability to have HIV, as ANC programs in Ukraine work effectively and the chance of failing to detect HIV during pregnancy is very small. In this case, medical workers should provide more clear messages about who can be at risk of HIV infection and who need to be recruited for such testing.

POTENTIAL FACILITATORS FOR HIV TESTING AND TREATMENT

Summary of facilitators of HIV testing and treatment that were mentioned during in-depth interviews are presented in the **table 5**.

Table 5. Facilitators of reaching people with HIV testing and getting them into HIV treatment

SERVICES IN MEDICAL SETTINGS	SUPPORTIVE SERVICES
<ul style="list-style-type: none"> ○ friendly attitude by staff; ○ symptoms and risk assessment; ○ high competence in HIV-related questions; ○ comprehensive HIV counseling; ○ psychological support during post-test counseling; ○ quick pathway to HIV care and treatment; ○ clear guidelines on how to start treatment. 	<ul style="list-style-type: none"> ○ participation in HIV prevention services (for PWID, former PWID): <ul style="list-style-type: none"> • staff attitude / friendly environment • provision services by former/current PWID; • sharing personal stories about their HIV diagnosis and treatment with peers; • anonymity; ○ monetary compensations; ○ HIV case management; <ul style="list-style-type: none"> • psychological support; • clear messages about HIV and treatment; • support and guidelines during HIV diagnosis – ART pathway.
OTHER FACTORS	COMMUNICATION MESSAGES THAT MIGHT HELP
<ul style="list-style-type: none"> ○ support from the family, «mothers always care»; ○ reduction of stigma and discrimination concerning PWID, alcohol users, PLWH, etc.; ○ confidentiality of HIV status, especially for small cities and rural places; ○ overall awareness about HIV acquisition risks for timely diagnosis. 	<ul style="list-style-type: none"> ○ less general ads; more targeted information from medical workers, social workers, personal stories from PLWH; ○ emphasis on a desire of any person to be healthy; ○ emphasis on a possibility to have a happy and healthy family; ○ provision of HIV test as a part of a package with other medical services and tests that might be less stigmatized; ○ reduction of stigma concerning HIV, more information that it can be treated and suppressed for further transmission; ○ information that ART intake is easy and effective; ○ more information in small cities and rural areas about HIV and testing sites.

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