

BARRIERS TO HIV TREATMENT AMONG PEOPLE WHO INJECT DRUGS:

A COMMUNITY
PERSPECTIVE
FROM KYRGYZSTAN
AND PAKISTAN

RESEARCH REPORT I APRIL 2019





This report is dedicated in loving memory of Syed Tariq Zafar and Ghazanfar Imam Rizvi. We thank them for their tireless efforts to ensure that the rights of people who inject drugs are upheld.

ABOUT

MISSING THE TARGET (MTT) REPORT SERIES

The Missing the Target (MTT) report series is part of ITPC's Watch What Matters campaign, which is a community-led monitoring and research initiative focused on capacity building and advocacy. Instead of waiting for researchers or development institutions to shed light on issues that have an impact on people living with HIV (PLHIV) and their communities, the power goes directly into the hands of affected communities. The MTT process includes empowerment of communities in research methods, provision of seed grants to undertake research, analysis, and development of the report. The MTT reports expose critical gaps in the HIV response earlier, and they empower people to advocate for solutions to these gaps.

Watch What Matters gathers data on access to, and quality of HIV treatment globally, with the aim to streamline and standardize treatment access data that communities collect. Through Watch What Matters, communities are empowered to systematically collect qualitative and quantitative data, analyse it and use it to inform and guide advocacy, and to ensure accountability.

To learn more about WWM and our work, visit **WatchWhatMatters.org**.

THIS REPORT

Missing the Target 12 (MTT 12) focuses on HIV treatment access barriers for people who inject drugs (PWID). This report – entitled Barriers to Accessing HIV Treatment Among People Who Inject Drugs: A Community Perspective from Kyrgyzstan and Pakistan – summarizes peer-led research conducted between December 2016 to December 2017 and the subsequent advocacy recommendations and activities to carry out throughout 2018 and 2019.

The MTT 12 report was jointly developed by the International Treatment Preparedness Coalition (ITPC), Mainline International and Nai Zindagi Trust in Pakistan; and with our partners ITPCru, AIDS Foundation East West (AFEW) International and Partnership Network Association in Kyrgyzstan, under the Bridging the Gaps - Health and Rights for Key Populations programme.

PARTNERS

ITPC

The International Treatment Preparedness Coalition (ITPC) is a global network of people living with HIV and community activists working to achieve universal access to optimal HIV treatment for those in need. Formed in 2003, ITPC actively advocates for treatment access across the globe through the focus of three strategic pillars:

- Treatment education and demand creation (#TreatPeopleRight)
- Intellectual property and access to medicines (#MakeMedicinesAffordable)
- Community monitoring and accountability (#WatchWhatMatters)

To learn more about ITPC and our work, visit itpcglobal.org.

ITPCru

Since 2005, ITPCru has worked in Eastern Europe and Central Asia (EECA) to maximize the involvement of people living with HIV in decision-making processes that concern their lives. ITPCru focuses on three main areas of work at local, regional, national and international levels:

- > Strengthening and mobilizing communities of people living with HIV to achieve universal access to treatment.
- Carrying out advocacy to improve policies, strategies and systems related to HIV and other associated diseases.
- Increasing community knowledge on HIV treatment and common co-infections through trainings and treatment education.

To learn more about ITPCru and our work, visit itpcru.org/en.

MAINLINE INTERNATIONAL

Mainline has worked extensively for over 25 years in the Netherlands and abroad to improve the health and rights

of people who use drugs. Mainline shares its experiences with local organizations, provides health education, capacity strengthening and support for best practices across regions, in collaboration with organizations dedicated to the principle of harm reduction. To learn more about Mainline, visit mainline.nl.

AFEW INTERNATIONAL

AIDS Foundation East West (AFEW) International is dedicated to improving the health of key populations in society. With a focus on Eastern Europe and Central Asia, AFEW strives to promote health and increase access to prevention, treatment and care for major public health concerns such as HIV, tuberculosis (TB), viral hepatitis, and sexual and reproductive health. To learn more about AFEW, visit afew.org.

NAI ZINDAGI TRUST

Nai Zindagi Trust (NZ) is a non-governmental organization established in Pakistan in 1989. It focuses on rights-based health and social services for persons affected by drug use and HIV. It provides comprehensive harm reduction, HIV prevention and access to HIV care, treatment and support services to PWID and their spouses in 30 districts of Pakistan, with a primary focus on harm reduction services. To learn more about Nai Zindagi Trust, visit naizindagi.org.

PARTNERSHIP NETWORK ASSOCIATION

The Harm Reduction Association Network, or 'Partnership Network Association' as it is known in Kyrgyzstan, is a national non-governmental organization (NGO) that advocates for the institutionalization of equal rights and better health for all. The Partnership Network consults with its 26 member-organizations, which operate throughout Kyrgyzstan, working together to influence national policy. Its prevention and advocacy programs cover HIV, tuberculosis and hepatitis C virus (HCV), focusing on the most marginalized and vulnerable groups including sex workers and injecting drug users.

ACKNOWLEDGEMENTS

ITPC recognizes the tireless efforts of Nai Zindagi Trust and the Partnership Network in implementing the activities highlighted in this report, as well as Mainline and *AFEW* for supporting the work of the respective partners. We wish to express our particular thanks to all health workers and community activists involved in data collection – including the Association of People Living with HIV-Pakistan (APLHIV), who worked in close partnership with Nai Zindagi Trust.

ITPC, Mainline and AFEW are alliance partners of Bridging

the Gaps – Health and Rights for Key Populations. This unique programme addresses the common challenges faced by sex workers, people who use and inject drugs, and lesbian, gay, bisexual and transgender people in terms of human rights violations and accessing much-needed HIV and health services.

Go to: **hivgaps.org** for more information.

ITPC also appreciates core support from the Robert Carr Fund and Open Society Foundations.

CONTENTS

Foreword
Executive Summary 2
Abbreviations and Acronyms
PART 1 Barriers to ART Access faced by PWID in Kyrgyzstan
Background
Study Methodology 5
Findings
Study Results
PART 2 Barriers to ART Access faced by PWID in Pakistan
Background
Study Methodology
Findings
Study Results
PART 3 Advocacy Recommendations 16
Endnotes





FOREWORD

As of December 2017, an estimated 21.7 million people living with HIV (PLHIV) were receiving antiretroviral therapy (ART).¹ But global and regional data mask national and local disparities and immense inequalities in ART access across communities and among key populations, including people who inject drugs (PWID).

Community-led monitoring can deliver more accurate and complete information about the realities that PLHIV experience. It empowers recipients of care, civil society and communitybased organizations to gather and provide valuable information on access to, and availability and quality of HIV treatment services. This information can be used to increase oversight of, and advocacy for improved HIV services - and for holding health systems accountable.



The Missing the Target (MTT) report series elevates the voices of civil society, community advocates and people living with HIV. MTT reports are supported by small grants for capacity building, research, and advocacy. The outputs include research reports and advocacy activities. To read previous MTT reports, visit itpcglobal.org/resources.

EXECUTIVE SUMMARY

report (MTT 12) uses a community-led approach to document key HIV treatment barriers that are faced by people who inject drugs (PWID). MTT 12 is based on research conducted by organizations of people living with HIV (PLHIV) in Kyrgyzstan and Pakistan, with support from ITPC, and in partnership with Mainline and AFEW International. Together, these organizations documented access to, and quality of HIV services among PWID and the stigma, discrimination, and disclosure issues that they grapple with. The MTT 12 findings highlight common barriers and identify advocacy priorities for HIV

The Missing the Target 12

> In Kyrgyzstan, Partnership Network focused their research on barriers to initiation of, and adherence to ART among PWID. They conducted interviews with over three hundred PWID who were living with HIV, as well as NGO representatives and healthcare professionals. Research covered Kyrgyz policy and legal frameworks, access to and coverage of HIV prevention and treatment services and compliance with national and international treatment guidelines. The results were analysed to determine the impact of these factors on the lives and health of PWID.

The key findings included:

- > PWID are being left behind when it comes to ART initiation. Despite the World Health Organization (WHO) 'treat-all' recommendation for everyone living with HIV, the median interval between receiving an HIV diagnosis and starting ART was 2.4 years among PWID, versus 84 days among non-PWID.
- Gaps in linkage to, and challenges with engagement in care create significant barriers to ART adherence among PWID. Among the 321 people included in this study, only 22% reported ART adherence, versus the national estimate of 83.7%. The most common reasons mentioned for ART interruption were lack of medicines (e.g. running out of stock while traveling or while in prison), consumption of psychoactive substances and treatment side-effects.
- > Communities are critical in supporting ART adherence. PWID who had access to peer counselling and psychosocial support during linkage to care, and those who had received services from an NGO, had significantly better adherence than those who did not.
- In Pakistan, Nai Zindagi's research focused on barriers to ART initiation, adherence and treatment monitoring, and issues with disclosure, stigma and discrimination. The study looked at two cohorts of PWID: 500 who were participating in an ART adherence program, and 100 program graduates. This research indicated that:

policies and services.

- ➤ Long-distance travel and lengthy waiting times for services at ART centres are significant barriers to HIV treatment among PWID. Seven percent (7%) of the 249 survey participants who had initiated treatment reported challenges with ART access, the most common concerns were lengthy travel to another city (41%) including paying for travel (10%), and long waiting times (38%). Similarly, among the 42 program graduates who reported difficulties receiving ART, 75% pointed at the long distances to ART centres.
- > Lack of awareness and knowledge about HIV negatively impacts treatment access and uptake among PWID. Of 500 PWID interviewed, 36% reported a lack of knowledge about HIV and noted that they delayed ART initiation based on the incomplete information they received from health facilities.

> Routine viral load testing (RVLT) needs to be urgently scaled-up: Only 18 respondents out of 200 had ever received a viral load test, and only 3 people in this group received their results.

Based on these findings, national-level recommendations to improve ART coverage and adherence among PWID in Kyrgyzstan and Pakistan were developed.

ABBREVIATIONS AND ACRONYMS

AAU	ART Adherence Unit (at Nai Zindagi Trust)
APLHIV	Association of People Living with HIV-Pakistan
ART	Antiretroviral Therapy
ARV	Antiretroviral
BTG	Bridging the Gaps Programme
DSD	Differentiated Service Delivery
EECA	Eastern Europe and Central Asia
HCV	Hepatitis C virus
HIV	Human Immunodeficiency Virus
ITPC	International Treatment Preparedness Coalition
ITPCru	ITPC Eastern Europe and Central Asia
LGBT	Lesbian, Gay, Bisexual and Transgender people

MTT	Missing the Target Report Series
NGO	Non-Governmental Organization
NSP	Needle-syringe exchange program
NZ	Nai Zindagi Trust
OST	Opioid Substitution Therapy
PAS	Psychoactive Substances
PLHIV	People living with HIV
PWID	People who inject drugs
RVLT	Routine Viral Load Testing
ТВ	Tuberculosis
UNAIDS	The Joint United Nations Program on HIV/AIDS

BARRIERS TO ART ACCESS FACED BY PWID IN KYRGYZSTAN



BACKGROUND

In Kyrgyzstan, PWID are the population which is most affected by HIV: prevalence in this group is 14.3% -versus 0.2% among the general adult population.² Shockingly, despite the 2015 WHO 'treat-all' recommendation, which is based on both the individual benefits of treatment and evidence that it reduces onward transmission of HIV, only 13.8% of PWID living with HIV are currently receiving ART.³

The Partnership Network Association's study sought to assess ART initiation among PWID and identify barriers to ART adherence to inform recommendations for improving national-level ART coverage.

STUDY METHODOLOGY

This research used a combination of qualitative and quantitative methods:

- ▶ Desktop Review. A document analysis was performed to find information about legal and policy frameworks, including compliance with national HIV policies and international recommendations (WHO, 2016); geographic coverage of HIV services; national HIV prevalence and coverage of prevention programs, and to identify areas for improvement.
- > Survey among PWID living with HIV (321). Individual respondent surveys were conducted using a standardized questionnaire which covered knowledge about HIV, experiences with stigma and discrimination, and access to, and availability, quality, cost, of ART; adherence to ART, and additional factors that had an impact on HIV services. Survey results were used for a comparative analysis between people living with HIV who inject drugs and PLHIV who do not inject drugs.
- In-depth interviews with key stakeholders and NGO representatives (16). These key stakeholders provided information about the structure and components of the HIV service delivery system, the legislative environment, funding and opportunities for provision of more integrated services etc.
- ▶ In-depth interviews with healthcare professionals (21). 15 physicians and 6 visiting nurses from 5 facilities were interviewed to collect detailed information about HIV service delivery processes, treatment education, social support services, referral to other services, and problems with service delivery.

This study was conducted with the approval of the Ethics Committee of the Ministry of Healthcare of Kyrgyzstan. Protection of personal data and confidentiality were ensured at all stages of the study, analysis and distribution. Measures were taken to ensure respect for, and dignity of everyone involved in the study.

FINDINGS4

Study Participant Demographics

TABLE 1

SEX	
Male	85%
Female	15%
AGE	
18-25	1.2%
26-35	14%
36-45	55.8%
46-55	22.4%
56 and older	6.5%
EDUCATION	
No formal education / primary education	18%
Secondary or vocational education	75%
Higher education (complete or incomplete)	7%
RELATIONSHIP STATUS	
Single	49%
Married	50%
LIVING SITUATION	
With family members	90%
Other	10%
EMPLOYMENT AND MONTHLY INCOME	
EMPLOYED	60%
6,000 to 10,000 Som (US\$90 – 150)	28%
11,000 to 20,000 Som (US\$158 - 286)	17%
21,000 to 50,000 Som (US\$300 - 715)	7%
UNEMPLOYED	40%
Up to 5 000 Kyrgyz Som (US\$75)	19%
Unemployed without income	30%

Linkage to Care & ART initiation

In 2015, led by a strong evidence base supporting the individual and public health benefits of ART, WHO issued a 'treat-all' recommendation for people living with HIV.⁵ Since then, many programs have adopted a 'test-and-treat' approach, or used other methods for prompt, post-diagnosis linkage to HIV care, treatment and services.

In Kyrgyzstan, among the PWID surveyed, the median period between receiving an HIV diagnosis and ART initiation was 2.4 years, versus 84 days for PLHIV who do not inject drugs as shown in Figure 1. Furthermore, most respondents (57%) were at stages 3 and 4 of HIV when they applied for treatment which may also point to their late linkage to care.

The most common factors that influenced ART initiation among PWID were a medical condition (74%); a doctor's counselling (65%); fear for one's life (52%); fear of infecting others (43%); fear of infecting his/her sexual partner (34%); and counselling from an NGO employee (39%). Other reasons included examples from other PLHIV, information from friends, colleagues, or the Internet.

Retention in Care

Once linked to care, PWID face challenges that make it difficult for them to remain engaged in care and adherent to ART. In Kyrgyzstan, the adherence rate among all people living with HIV ranges from 50-93.5%; it was only 22% among the PWID surveyed.⁶

Adherence to ART was significantly- and alarmingly-low among PWID in the Sokuluk (12%), Ysyk-Atin (14%) and Zhaiyl (15%) regions. In all sites studied, ART adherence ranged from 12% to 30%, in sharp contrast to the national rate of 83.7% (which ranges from 70.5% in the Chuya region to 100% in the Issyk-Kul region).

Low adherence rates can lead to suboptimal treatment outcomes including HIV drug resistance and treatment failure and progression to advanced HIV disease, which leaves people highly vulnerable to illness and death.

Inadequate access to ART, and lack of adherence support not only endanger individual health – they limit the prevention benefit of HIV treatment. Furthermore, availability of and access to opioid substitution therapy (OST) – which reduces the risk for HIV and HCV - remains dangerously low, at 4.9% versus the WHO recommendation for coverage, which is 40 per 100 PWID.⁷

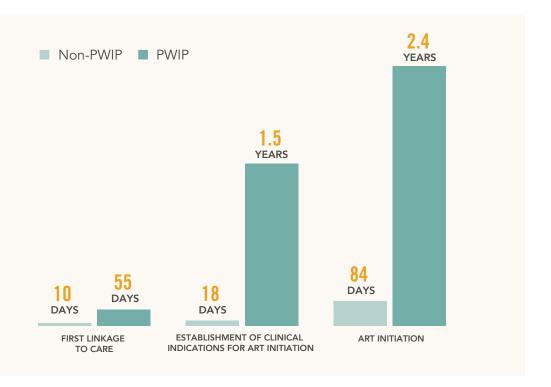
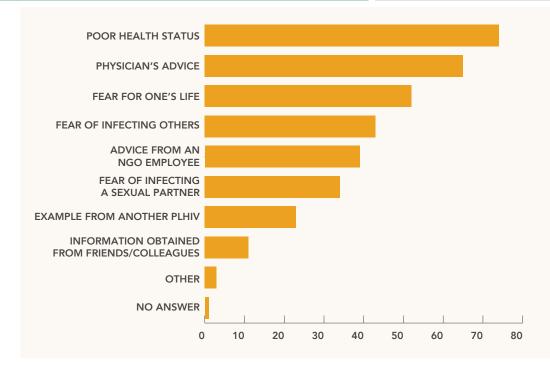


FIGURE 1
Median period from HIV
diagnosis until first linkage to
care, establishment of clinical
indications for ART, and ART
initiation.

FIGURE 2
The reasons for deciding to initiate ARV therapy



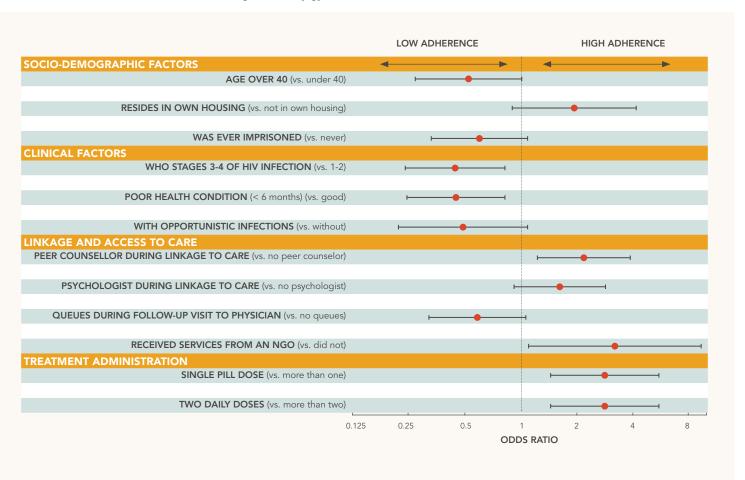
Twelve factors associated with low adherence were tested using an adjusted logistic regression model (Figure 3 on next page). Results showed that lower adherence to ART was significantly associated with PWID who didn't receive peer counselling during linkage to care and with those who had never received services from an NGO (such as syringe exchange services, condom distribution, alcohol wipes, testing, counselling, information services, support, referral of clients.) As well as social services. Although not statistically significant, higher adherence was associated with respondents residing in their own housing, those that reported no queues during follow-up visits to physicians, and those that had never been imprisoned.

According to the national HIV infection e-monitoring system, PWID interrupted their treatment 1.5 times more often (22%) than PLHIV who did not inject drugs (15%). There were several reasons for ART interruptions, including side effects (see Figure 4 on following page). Overall, 29% of survey respondents stopped because of side effects that included nausea (11%) depression (8%), impaired coordination (7%), sleep disturbances and vomiting (7%). Over a third of respondents (36%) reported ART interruptions due to lack of medicines (for example by running out of stock during trips away from home, misplacing the medicines, or unable to access them due to imprisonment). Further research is needed to shed more light on this issue, but the current results speak to insufficient counselling and information, as well as lack of awareness of the risks associated with interrupting treatment.

Survey respondents faced additional barriers pointing to the lack of differentiated service delivery (DSD) – which is adapted to the health and needs of PWID. For example, 50.5% of those who interrupted ART reported that they were not permitted to have someone else pick up their medicines if they were unable to go to the health facilities themselves, and 67.4% reported that they could only receive ART from a single institution in the city or region where they were registered.

Long queues during follow-up visits with doctors or physicians created an additional barrier for PWID. Thirty-two percent of the respondents reported waiting 15 to 30 minutes, and 8% reported waiting more than half an hour to see a doctor. Waiting times increased the risk of being identified by acquaintances who could disclose their HIV status to family and friends, and the study shows that respondents who reported no queues during follow-up visits to physicians were more likely to be adherent. In addition, survey respondents found medical settings to be unpleasant, and their confidentiality was not always protected. Overall, 13% of survey respondents reported difficulties with getting an appointment with other medical specialists, such as a surgeon or gynaecologist, due to their HIV status and/or drug use. Among those, 62% experienced rudeness from staff, 38% complained about disclosure of their HIV status, and 36% were refused services entirely.

FIGURE 3
Factors associated with low adherence among PWID in Kyrgyzstan, 2017 (n=321)



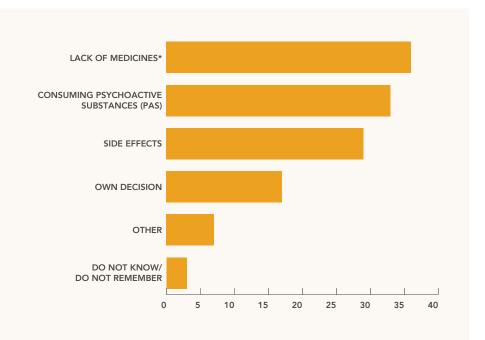


FIGURE 4
The reasons for interruption of the ART according to the respondents.

^{*}Lack of medicines includes medicines lost or misplaced, person being away from home, ran out of stock while away from home or in prison.

STUDY RESULTS

ART service delivery is currently inconvenient and time-consuming for recipients of care who inject drugs.

Introducing differentiated service delivery (DSD) models, such as community ART groups, and strengthening decentralized healthcare services within non-governmental organizations could help to address these issues. Services should increase involvement of PWID to provide peer counselling and support services for PLHIV, as well as task-shifting of HIV care liaison functions to NGOs which have broader access to PWID.

THE RESULTS FROM KYRGYZSTAN HIGHLIGHT SEVERAL IMPORTANT ISSUES



Health care providers must be supportive and need capacity building and incentives to deliver more comprehensive quality services.

This includes improving their competence in performing post-test counselling and ART adherence support. Introducing indicators to assess the quality of post-test counselling and/or systems to incentivize physicians for maintaining high quality care may be helpful.

Advocacy is needed to improve OST programs.

The current OST program is not attractive for PWID, with poor outreach efforts and inadequate staffing. An integrated approach is required, including delivering methadone and ART through a single window.

BARRIERS TO ART ACCESS FACED BY PWID IN PAKISTAN



BACKGROUND

As in most parts of the world, PWID in Pakistan remain disproportionately affected by HIV and HCV. Prevalence is estimated at 21% for HIV and 53.6% for HCV among PWID, versus 0.1% and 6.2% respectively among the general population.^{8,9} Unsurprisingly, these epidemics have been fuelled by the lack of quality prevention and harm reduction services. The available health services do not adequately meet the diagnostic, treatment, care or support needs of PWID. Only recently - in January 2018 – did the Ministry of Health in Pakistan initiate an HIV 'treat-all' policy, although it has been recommended by WHO since 2015.

While the country struggles to implement evidencebased strategies with limited resources, PWID continue to face severe access barriers to life-saving HIV treatment.

About Nai Zindagi's ART Adherence Unit

Nai Zindagi provides care services through the ART Adherence Unit (AAU), a residential rehabilitation facility for PWID. The AAU, which opened in 2014, combines treatment for opioid dependence with support for adherence to HIV treatment. The AAU aims to stabilize recipients of care with opioid substitution therapy (OST) which facilitates HIV treatment. The 4 to 6-week residential care program has a fixed schedule of daily activities, including individual and group therapy sessions, lectures and presentations on various topics around HIV/AIDS, sessions on psychosocial issues such as family reintegration and relapse prevention, family call time and diary writing. AAU graduates return to their home cities and register at public ART clinics, where community outreach workers follow up on adherence issues with recipients of care and their families.

STUDY METHODOLOGY

Nai Zindagi's study sought to assess barriers to HIV services and treatment for PWID in Pakistan. The research focused on major obstacles to ART initiation, adherence, and treatment monitoring, as well as issues specific to disclosure, stigma and discrimination.

A standardized questionnaire was administered during confidential interviews among PWID receiving care through NZ. The study population consisted of two cohorts:

- > Cohort 1 (current adherence program participants) included 500 AAU residents who had undergone detoxification and been initiated on ART; they had access to therapeutic and medical services at the AAU. The AAU was used as the central data collection site. The questionnaire was administered by psychologists during the recipient of care's third week at the AAU, according to their stability.
- > Cohort 2 (adherence program graduates) was made up of 100 people who had graduated from the residential program at least 6 months before the study started. Questionnaires were administered via telephone interviews by a Nai Zindagi project coordinator. Every third recipient of care was interviewed, and the call was recorded. Hard data files with questionnaires from both cohorts were maintained.

The study protocol obtained ethical approval from the Pakistan Medical Research Council (PMRC) and followed international standard measures to protect individuals' rights and ensure safety of all study participants - including maintaining confidentiality and ensuring informed content.

FINDINGS

Characteristics of Cohort 1 Study Participants

TABLE 2 Study Cohort 1 Demographics

AGE	
19-30	59%
31-35	22%
35-40	12%
41 and older	8%
EDUCATION	
No formal education	42%
Primary education	23%
Secondary education	31%
Higher education (complete or incomplete)	4%
RELATIONSHIP STATUS	
Single	47%
Married	28%
Divorced, separated or widowed	14%
LIVING SITUATION	
With family members	90%
With friends	2%
On street	6%
Other	2%
SOURCE OF INCOME	
Daily wages	49%
Self-employment	26%
Salary	15%
Financial support by others	7%
Other	4%

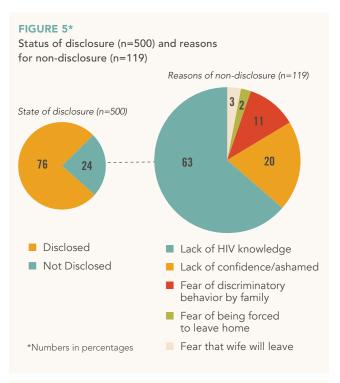
HIV Disclosure & ART initiation

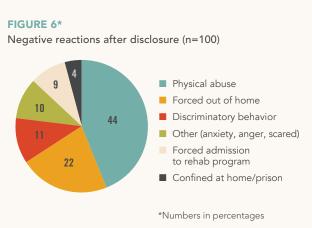
As shown in Figure 5, 76% of the 500 people surveyed had disclosed their HIV status to a family member; 41% of them reported a supportive reaction and some respondents received financial support from relatives,

including for drug treatment. Of the 26% who received negative reactions to the disclosure of their HIV status, 44% reported physical abuse, and 22% were forced, to leave home (Figure 5).

Of those who had not disclosed their HIV status to their family (119), 63% mentioned 'lack of knowledge about HIV' as being the main reason for non-disclosure. Respondents reported that although outreach workers and social mobilisers provided information, they either could not retain this information or did not understand its importance, due to chaotic drug use, and 37% cited fear, stigma, discriminatory behaviour and a high likelihood of violence as their reasons for non-disclosure.

Although WHO has recommended ART for all people with HIV, PWID did not initiate it immediately. Most respondents started ART more than 30 days after



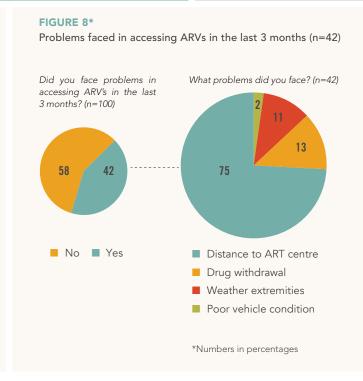


Reasons for gaps between HIV diagnosis and ARV initiation (n=500)

Lack of awareness about possible harms of HIV

Drug use
Incomplete information by CoPc+ staff
Imprisonment
Non-supportive behavior of family
Abscess/Health-related
Family boycott

*Numbers in percentages



receiving their HIV diagnosis, with 32% of all respondents waiting more than four months. As shown in Figure 6, the most common reasons for this delay were lack of awareness of HIV (36%) and drug use (33%). Once they started ART, most survey respondents (93%) did not face difficulties registering at ART centres. Among the 7% who reported issues during registration, the most common concerns were lengthy travel to another city (41%) - and paying for travel (10%), long waiting times (38%) and drug withdrawal (15%).

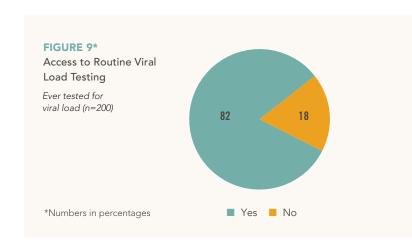
Retention in Care

A second cohort of the study involved one hundred (100) respondents who had completed Nai Zindagi's AAU residential program and returned to their cities of origin for at least six (6) months before being interviewed.

Overall, 28% of them received their HIV treatment directly from ART centres, and 72% from Nai Zindagi's services. Of the 100 respondents, 44% missed a dose of their ART during the last three months, with most of them (73%) indicating that this was because they were away from home (either for professional reasons, family matters, or imprisonment). Treatment was stopped or interrupted by 14% of respondents because of concerns that using illicit drugs with ART could cause harm or death. Forty-two respondents reported barriers to ART access during the last three months – including

long travel distances to ART centres (75%), drug withdrawal (13%) and poor weather conditions (11%).

Thirty-eight percent reported ART side-effects. Anxiety was the most common symptom (54%), followed by dizziness (25%) and diarrhoea (21%). Just over half of survey respondents reported stigma of being a drug user and a person living with HIV as the major reasons for discrimination by medical staff - including refusal to provide treatment. Although 44% of respondents indicated they knew the importance of viral load tests, only 18% of them reported having received one. Of these, only three were informed of their results.



STUDY RESULTS

Long distances to and waiting times at ART centres continue to be significant barriers to HIV treatment for PWID

Out-of-facility individual models and community ART groups could help address these issues and improve linkage to, and retention in care. Service delivery must be tailored to the specific needs of adolescents and young adults who inject drugs: Fifty nine percent (59%) of cohort 1 were between 19-30 years of age, suggesting a younger population at risk.

Lack of awareness and knowledge about HIV impacts treatment access and uptake.

As an example, some survey respondents believed that they could not safely use illicit drugs with their ART and interrupted it to avoid harm. Health facility staff need training on HIV, including importance of ART adherence and drug use with ART. Materials with this information need to be available for recipients of care.

THE RESULTS FROM PAKISTAN HIGHLIGHT SEVERAL IMPORTANT **CONCLUSIONS**

Routine viral load testing (RVLT) needs to be scaled up.

Few treatment centres are equipped to provide RVLT, few people are accessing it, and an even smaller group are receiving their results. Advocacy with National and Provincial AIDS Programs and ART clinic staff is needed to increase access to RVLT.

Advocacy for and dialogue around OST should be intensified

The gap between ART initiation and registration has been reduced by the 'treatment for all' initiative, with only 7% of cohort 1 respondents facing difficulties in getting ART. Respondents reported that they choose not to seek or delayed seeking treatment or services because of drug use; lack of access to OST and detoxification were identified as barriers to treatment. Programs that combine OST with HIV care have had success in other countries and should be explored as a valuable solution to better reach and retain recipients of care.

Widespread awareness campaigns, coupled with national laws and policies, are needed to effectively address stigma and discrimination

A quarter of cohort 1 members who lived with family had not disclosed their HIV status, primarily because of fear, stigma, discriminatory behaviour and likelihood of experiencing violence. Service providers need to further intensify support for disclosure and facilitate staff training to reduce negative reactions from family and/or community.

ADVOCACY RECOMMENDATIONS



Innovative service delivery models are needed to address barriers to care and treatment among PWID living with HIV

In both countries, ART service delivery is inconvenient and time-consuming for recipients of care. Differentiated service delivery (DSD), through out-of-facility individual models and community ART groups, could help address this issue and improve linkage to, and retention in care. Services should increase involvement of NGOs and PWID to provide peer counselling and support services for PLHIV. ITPC has developed an Activist Toolkit on Differentiated Service Delivery to help communities identify opportunities and advocate for these types of services.

Access to ART and OST for PWID are equally important and should be linked, to overcome the existing structural barriers that impact adherence

In both countries, lack and low of quality OST and detoxification programs were barriers to HIV treatment. The structural barriers within the health system make adherence challenging. Programs that combine services like OST with HIV care will be more successful in reaching and retaining recipients of care.

Treatment education is a vital for improving treatment access and increasing demand and uptake of HIV services - for recipients of care and their healthcare providers

Common reasons put forward by PWID for delaying ART initiation were lack of knowledge or incomplete information received from health care facilities. Treatment education is also needed to increase demand for access to quality HIV services such as RVLT.

ENDNOTES

- 1 WHO. Antiretroviral therapy (ART) coverage among all age groups. Global Health Observatory (GHO) data [Online] Geneva; 2017 [Cited 2019 February 26] Available from http://who.int/gho/ hiv/epidemic_response/ART_text/en/
- 2 UNAIDS. Country factsheets: Kyrgyzstan [Online]; 2019 [Cited 2019 February 26] Available from http://unaids.org/en/regionscountries/countries/kyrgyzstan
- 3 ibid
- 4 This report summarizes key findings from the PWID survey; the Partnership Network's full report provides the complete analysis from the document review, key stakeholder interviews, and healthcare provider interviews. https://itpcru.org/en/2018/04/25/kyrgyzstan-assessing-barriers-for-hiv-aids-treatment-coverage-expansion/
- 5 WHO. Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection: what's new. Policy brief [Online] Geneva; November 2015 [Cited 2019

- February 23] Available from https://apps.who.int/iris/bitstream/handle/10665/198064/9789241509893_eng.pdf;jsessionid=4CC0708B618F2B5EF7B1F86D875946CA?sequence=1
- 6 In this study, ART adherence was calculated with the following formula:

Calculation of missed doses:

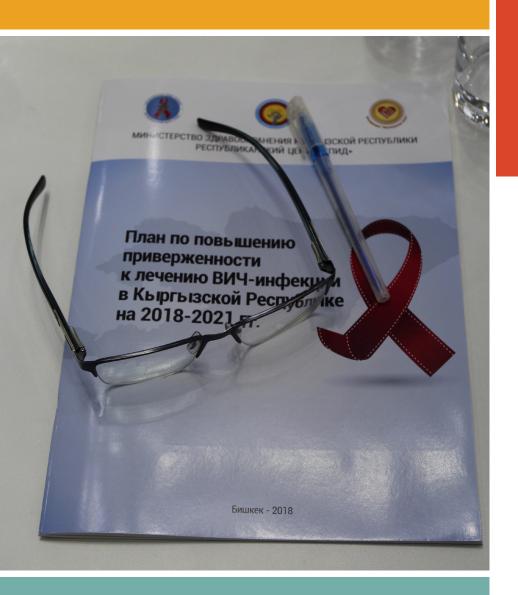
No. of days of taking – Nos of the tablets assigned

No. of days of taking/30

- 7 WHO (2015), ibid
- 8 UNAIDS. Country factsheets: Pakistan [Online] Geneva; 2017 [Cited 2019 February 23]. Available from http://www.unaids.org/en/regionscountries/countries/pakistan
- 9 Zaina et al. The epidemiology of hepatitis C virus in Pakistan: systematic review and meta analyses. R Soc Open Sci. [Online]; April 2018 [Cited 2019 February 23] Available from https://www.ncbi.nlm.nih.gov/pubmed/29765698



This publication was developed with funding from Bridging the Gaps, and core support provided by the Robert Carr Fund (RCF) and Open Society Foundations (OSF).



Missing the Target report series is part of Watch What Matters, a community-led monitoring and research initiative to gather data on access to, and quality of HIV treatment globally. To learn more, visit WatchWhatMatters.org.











itpcglobal.org

