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**Qualitative Research among Most at-Risk populations for TB and HIV in USAID Dialogue on HIV and TB Project Pilot Sites in Kyrgyzstan**

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## 1. Abbreviations

PWID	People who inject drugs
SW	Sex workers
PLWH	People living with HIV
HIV	Human immunodeficiency virus
TB	Tuberculosis
FGD	Focus-group discussions
IDI	In-depth interview
ARV	Anti-retro virus therapy
PAD	Parents against drugs (NGO)
NGO	Non-governmental organization
GP	Grant of parole

## 2. Introduction

The USAID Dialogue on HIV and TB Project aims to increase access to HIV and tuberculosis prevention services among most-at-risk populations (MARPs) who are at-risk of getting infected with HIV and TB by providing technical expertise, training and outreach services. The Project combines the best practices and the most effective methods of work with MARPs to strengthen control of HIV and TB in the region. It is also based on performance results and the expansive experience of partners, who are working with most-at-risk groups in each country of the Central Asia Republic (CAR). The program is implemented by a consortium of partners led by Population Services International (PSI) and includes Project HOPE, AIDS Foundation East-West (AFEW) and PF “Kazakh Union of People Living with HIV/AIDS in RK”. The Project start date is September 30th, 2009.

Due to the growing epidemics of HIV and TB in the world, the USAID Dialogue on HIV and TB Project is targeting populations who are at higher risk of acquiring HIV and TB: people who inject drugs (PWID), sex workers (SWs), migrants and people living with HIV (PLWH).

A qualitative survey among representatives of the MARPs (PLWH, PWID, SW and migrants) was conducted under the project.

## 3. Objectives and tasks

The objective of the survey is to make a medium-term project performance assessment to evaluate the increase in the level of awareness about TB and HIV/TB among MARPs. The survey results will be used for making necessary changes in the project work plan in order to improve MARPs’ access to medical services on TB and TB/HIV.

### Tasks:

1. Level of knowledge, attitudes, practice and behavior related to tuberculosis and TB/HIV;
2. Obstacles in visiting medical institutions and getting treatment for tuberculosis
3. Motivation for applying for and getting treatment for TB;
4. Stigmatization;
5. Need for additional information about TB.

#### 4. Methodology

The survey was based on focus-group discussions (FGD) and in-depth interviews (IDI), conducted among target groups in Bishkek city, Chui, Osh and Djalal-Abad oblasts.

- Total number of FGDs was 12 with 10 participants in each group
- 20 IDIs were conducted with PLWH, who either had TB or went through TB within the last 12 months while being interviewed.
- Participants of FGD and IDI were provided with motivational packets/goods.

Guidelines on conducting FGDs and IDIs were provided by the USAID Dialogue on HIV and TB Project.

#### Summary table on the number of respondents

Pilot regions (oblast)	SW		PWID		PLWH		Migrants		Total number of participants	
	# FGD	# Participants	# FGD	# Participants	# IDI	# Participants	# FGD	# Participants	# FGD	# Participants
Bishkek	-	-	1	10	-	-	2	20	3	30
Chui	2	20	2	20	1	10	-	-	5	50
Osh	1	10	1	10	1	10	-	-	3	30
Jalal-Abad	1	10	-	-	-	-	-	-	1	10
<b>Total</b>	<b>4</b>	<b>40</b>	<b>4</b>	<b>40</b>	<b>2</b>	<b>20</b>	<b>2</b>	<b>20</b>	<b>12</b>	<b>120</b>

#### 5. Entry criteria

1. Must have been 18 years old or over (18 – and not older than 50 years old for PWID);
2. Males and females (only females for SW);
3. Adjusted criteria:
  - 3.1 PWID: injected drugs at least once for the last month, has experience of drugs injection – not less than 6 months;
  - 3.2 SW: provided sexual services for money or other material compensation within last 30 days;
  - 3.3 Migrants: must be a labor migrant, who returned to the motherland and who regularly migrates abroad or is a labor migrant within last 6 months;
  - 3.4 PLWH: is HIV-infected, ill with TB or was ill with TB last year.
4. Conscious and voluntary agreement to participate.
5. Must be covered by the pilot projects.
6. Did not participate in similar prevention programs earlier.

## 5.1. Summary of assessment results

### Sex workers

#### *The level of knowledge, practice and behavior related to tuberculosis and TB/HIV*

The majority of FGD participants characterized TB as a disease, which has two types – open and closed. A characteristic symptom of TB is having a cough, particularly, having a cough with phlegm. Other symptoms were listed as well: yellow color of face, chest pain, weight loss, and spitting blood.

Along with in-depth and substantive replies of most of the participants were replies which indicated unawareness about any symptoms of TB at all. Respondents explained their unawareness by the fact that they did not have any previous experience with TB. Such responses were given only in a few cases from respondents in the Chui oblast.

Most respondents mentioned that the main mode of TB transmission is through airborne droplets. Along with the right understanding of TB transmission, there were also some wrong ideas, too. For example: *“No, it is not transmitted through air. If tuberculosis could be transmitted through the air, then all the people would have become infected. There would be no healthy people in the world...”* However, such responses were rare.

According to the opinion of almost all FGD participants, an indifferent attitude towards TB will inevitably result in a fatal outcome. According to the absolute majority of participants, TB is curable. The majority think that at the early stage of TB a timely medical intervention can lead to a complete health improvement. Respondents’ answers regarding actions and practices of behaviors for the reduction of TB transmission showed that most people have a relatively in-depth understanding of the information, which included knowledge of high-calorie foods, hygiene, and other prevention measures.

Summing up the general TB-related understanding of FGD participants, the following is a quote from one of the respondents, which reflects the thoroughness and depth of understanding about TB of most FGD participants from this category, who were recruited into groups from pilot projects:

*There are two types of TB: open and closed. If a person has the closed type, it is not awful! If the person stays 2 months in the tuberculosis clinic and regularly takes medicines, he/she can become cured quickly. If a person has the open type, 100% chance is that that ill person will infect everybody.*  
*I think that if it is an early stage of TB and the ill person goes to a medical facility in time and will regularly take their medicines, then he is not dangerous for society.*  
*If a person follows all the prescriptions assigned by a doctor, TB is curable.*

It is necessary to point out that, overall, responses of participants from southern regions were more content-rich.

#### *Obstacles when referring to a medical facility and getting treatment for tuberculosis*

All the participants agreed that in the case of having TB symptoms, it is necessary to consult with a doctor. But some did not know, or named different doctors, when asked specialist it is necessary to consult with. Some participants mentioned opportunity of getting services in non-governmental organizations.

Participants of the western part of the Chui oblast unanimously stated that there are no barriers for applying for health care and treatment for TB.

Representatives of the eastern part of the Chui oblast listed financial difficulties as a barrier. Respondents from the Osh city listed the following difficulties (listed according to the frequency of being mentioned, from most to least mentioned): financial barriers; only specialized hospitals take care of this disease; lack of beds; lack of identity documents, cynicism of doctors, stigma; risks to lose clients.

It was mentioned that medical staff are more friendly during the medical examination when SW are accompanied by NGO representatives who have partner relations with them.

Participants' responses indicated that in general there are no issues in their interaction with doctors when they apply for health services and treatment for TB.

Some SW had the very strict opinion that it is necessary to take care of one's own health, in particular to make sure health issues do not create obstacles for their successful professional activity.

SWs responses on HIV indicate that representatives of southern regions have more comprehensive knowledge on HIV, whereas awareness of representatives from Chui oblast was more general.

Most females think that HIV testing is the only method to detect HIV.

All females are in agreement with the statement that a person who looks healthy can have HIV.

All participants from the Chui oblast do not know about antiretroviral (ARV) therapy, while participants from the southern regions were more informed.

Awareness about adherence to ARV, as well as knowledge of general information about ARV, is low in the studied sites of the Chui oblast. Almost all respondents said that they "do not know" about it. Some awareness was observed in the surveyed cities of the southern region of the country, specifically in regards to their understanding of how treatment adherence means strictly following the assigned schedule and regime of taking pills.

Representatives of Chui oblast showed limited awareness about AIDS. The situation in surveyed cities of southern regions of the country is a little bit better, compared with places of the Chui oblast.

The majority of females said that they "do not know" about the issue of TB/HIV co-infection (Chui, west and east). The respondents from southern regions had a higher and more precise awareness of this issue.

The majority of the surveyed females, in particular those from the western part of the Chui oblast, did not know about the impact of HIV on TB.

Those who had some awareness demonstrated vague and not specific knowledge of the issue. Respondents listed two ways to detect TB in PLWH: based on external symptoms and through medical tests. In regards to this question, **again, the majority of representatives** from the Chui oblast demonstrated poor knowledge. Also, participants stated that detection of TB in PLWH does not differ from detection of TB in the general population.

The majority of respondents from western part of Chui oblast do not have information about treatment of TB in PLWH. Very few of them attempted to reply and share their knowledge, but those who did reply lacked confidence in what they knew.

Almost all respondents mentioned the importance of adherence to TB treatment. In their opinion, adherence is important for their health, longer living and is also important for not transmitting TB to others.

### ***Motivation for applying for and getting treatment from TB***

The main motivational factors for referring to a doctor to start TB treatment are having an understanding of the value of one's own health and receiving care from close people and relatives. Most FGD participants highlighted the importance of moral support from their relatives and friends, and some pointed out the important role that doctors also had in giving support. Some also noted the necessity of financial support.

### ***Stigmatization***

According to the respondents the following people are at risk of getting TB: 1) people who have unfavorable living conditions; 2) people with bad health habits; 3) nobody is safe from not getting infected with TB. Some other causes were also listed—alcohol consumption, smoking, and not caring about one's own health.

In general, the attitude of SWs towards people with TB is quite loyal. They mainly treat them with understanding, and some with sympathy. Many respondents (mainly from southern regions) in their life have met and continue to meet people with TB, and these people turn out to be their friends and close relatives.. The vast majority of participants would continue being friends with someone diagnosed with TB, while others responded that they would still keep relations but would communicate indirectly (they would, for example, communicate through the phone). Very few stated that they would not continue their relationships with someone who has TB.

Respondents, particularly those from the Chui oblast, mentioned the need for information about TB. Russian and Kyrgyz languages were indicated as preferable languages. Discussions, (during which clarifications can be made), printed materials and video clips were listed as preferable sources for information.

### **People who inject drugs**

#### ***The level of knowledge, practice and behavior related to tuberculosis and TB/HIV***

Regardless of the region, respondents have a profound knowledge of TB. Their replies were thorough, complete, and include information about TB symptoms and modes of its transmission.

When reviewing the main modes of TB transmission, respondents attempted to link the mode of transmission with the type of TB. Airborne droplet transmission was mentioned as a main mode of transmission. According to the majority of respondents, in the case of an advanced disease, the outcome is lethal. All FGD participants agreed that TB is curable, but also depends on the stage of the disease at diagnosis and whether it is treated correctly. Curability is mainly determined by the sick person's responsibility for their own health. Some respondents were aware about resistant types of TB. They thought that resistant types either cannot be cured at all or are difficult to be cured.

There were also opinions that it is impossible to cure TB fully, but it can be “deadened” and length and quality of sick person’s life depend on persons’ healthy habits.

Respondents were well aware of measures, which prevent TB transmission—in general, all the measures were listed, including: apply to a doctor as one develops first symptoms, preventive measures, eliminate harmful habits, inform people around about TB.

The places to apply when developing TB symptoms included medical institutions or non-governmental organizations. Some respondents mentioned non-traditional treatment.

### ***Obstacles when applying to a medical institution and getting treatment for tuberculosis***

Respondents mentioned no obvious obstacles when getting health care. Some of them, however, had mentioned: stigmatization, financial problems, lack of necessary information, and self-treatment. Many respondents did not see any barriers in getting treatment when applying for medical care, except in cases when they did not have specific documents. Many respondents again indicated that being accompanied by a social or outreach-worker greatly eases the process.

Respondents demonstrated knowledge about HIV and modes of its transmission.

According to the majority of respondents, HIV testing is the only way for HIV detection, and they unanimously said that a person who looks healthy can have HIV.

In general, respondents have knowledge about ARV therapy. Almost all respondents were aware of the importance of treatment adherence as well as the importance of strictly following the treatment regimen.

Many respondents know that AIDS is the last stage of HIV infection and were aware of the difference between HIV and AIDS. PWIDs were aware about HIV/TB co-infection. Most of them had a complete and correct understanding of the interaction between the two diseases, and knew that TB is one of the main concomitant HIV diseases. Respondents were informed that not adhering to treatment will eventually lead to resistant types of TB.

### ***Stigmatization***

According to the majority of PWID, almost all people have an equal chance of being infected by TB. Many PWID are convinced that TB is more easily spread among vulnerable groups of people. Almost all respondents knew someone with TB. To the question, “Do you know somebody who had or has TB?” all PWID answered – “We know and are in contact”. Attitudes of PWID towards people with TB are, in general, loyal. However, some of them have a fear of being infected.

At the same time, almost all PWID responded that they would continue to be in contact with people with TB. According to them, the reasons behind getting TB are stigma and lack of required information.

They had mentioned that those on TB treatment need to be supported financially and morally, and be supported by outreach-workers. They mentioned the need to improve doctors’ attitudes towards them, and the need for assistance when they try to recover necessary documents related for getting treatment.

### ***Motivation for applying to and getting treatment for TB***

The main motivation for PWID getting treatment from TB is the health of people close to them, specifically the fear that they will infect them.

The most preferable information channels listed were disks, brochures, leaflets. Meetings with health specialists, where they would have the opportunity to ask questions and get answers, were also listed.

The need for additional information was also expressed. In general, they noted that they have all the necessary information, but are not sure that it is complete.

The preferred language for materials that have information about TB depend on the location of respondents. In Bishkek and Sokuluk the Russian language is preferable, and in Osh they prefer Russian, Kyrgyz and Uzbek languages.

## **Migrants**

### ***The level of knowledge, practice and behavior related to tuberculosis and TB/HIV***

Migrants demonstrated a thorough knowledge about TB. Participants indicated that this disease is infectious and is transmitted through airborne droplets. The following basic symptoms were listed: cough temperature, sweating, loss of weight and appetite. The main transmission ways listed were: airborne droplets, through sneezing or cough, dishes, kisses, etc. According to most migrants, TB can lead to death, disability and other diseases. They responded that this happens when a person does not follow their prescribed regime of treatment and hygiene measures. Most FGD participants had difficulties in answering a question regarding the treatment period of TB. Some respondents think that treatment takes 6 months and more. According to almost all respondents, TB is curable if relevant measures are taken in time.

The range of answers to a question regarding measures for reducing TB transmission included: wearing masks, hygiene, and preventive measures. Particularly, each person should pay appropriate attention to TB prevention measures to be implemented through regular examination for TB.

Most participants were tested for TB within last 12 months, when being employed, during pregnancy, etc. However, some migrants were not tested within the last 5 years. All the respondents who tested said that if a person has TB symptoms, he must consult a doctor.

### ***Obstacles when applying to a medical institution and getting treatment for tuberculosis***

The main factors which hinder applying for aid and getting treatment for TB among migrants are various general circumstances and the lack of funds. Almost all respondents did not see any barriers in **self-applying** to a medical institution when having TB. When it comes to detecting TB symptoms, migrant respondents thought that barriers can be stigma, thinking mode and financial problems.

According to most migrants, the doctors' attitude, both to a patient and related to their professional duties, plays an important role. All respondents unanimously answered that HIV stands for the human immunodeficiency virus. Some were informed about its incurability and transmission ways. All the respondents said that HIV testing is the only way of HIV can be detected. The vast majority of respondents are not aware of a "window period". Only one female participant answered this question, which indicates at low awareness among respondents about this issue.

According to most migrant respondents, a healthy-looking person can have HIV as well.

Answers of some respondents on when they went through HIV testing the last time showed that due to certain circumstances they do not adhere to the principle of regular HIV testing.

All the migrant respondents had HIV test results, except one. Only one participant answered that ARV therapy means treatment. Another person thought that ARV therapy means consultation. It was difficult for other FGD participants to answer this question. No participants were aware of importance of adherence to ARV therapy.

Respondents are not aware of such a term as “HIV/TB co-infection”. Only a small share of respondents replied to a question regarding the impact of HIV infection over development of tuberculosis. These replies were of a general character.

According to migrants, TB in PLWH is detected by testing, i.e., does not differ from the detection of TB in the general population. TB must be treated under a doctor’s control. Particularly, answers of respondents indicate that there is no difference in treatment for TB in both PLWH and the general population.

Most respondents did not have any idea about resistant types of TB. Only one respondent from two FGDs shared information about this issue.

### ***Stigmatization***

The majority of migrants think risk factors for TB are different life circumstances and living conditions that foster TB transmission. People with TB among migrants invoke sympathy. Some respondents have friends and relatives with TB. Some participants have friends who died from the disease. Many answered that they know, are in contact with, and support those people with TB.

### ***Motivation for seeking and getting treatment for TB***

The main factor which encourages migrants to seek medical services is the value of their own health. Support is an important factor for migrants when being treated for TB. But almost all are of the opinion that the support from family is the most important.

In general, the majority of respondents of migrants mentioned that there is no need for additional information. However, some of them indicated the need for getting more detailed information about TB.

Migrants prefer to get information in the Kyrgyz language. TV channels, printed mass media, and disks were listed as the main channels for presenting information related to TB transmission.

### **People living with HIV**

The following TB symptoms were listed by people living with HIV (PLWH) as being the main ones: weakness, high temperature, night sweating, coughing for 2 or more weeks, blood spitting, pain in the chest, and weight loss. It is necessary to point out that PLWH described the symptoms which were detected when having TB. Most surveyed PLWH were infected by TB at prisons. Regular examination of prisoners in Kyrgyzstan allowed for the detection of TB. PLWH respondents listed the following reasons for being infected with TB: poor nutrition, sharing dishes, syringe, and coldness. Some PLWH worked in Russia, and according to them the main reasons of getting TB were related to labor conditions, such as coldness and regular alcohol consumption. Some respondents also mentioned partners and sharing syringes.

Almost all respondents unanimously said that there is a possibility to recover completely from TB, if following prescribed treatment. Also PLWH are well aware of the necessity to follow hygiene measures, calorie-based diet, and healthy living conditions.

### **Place for aid addressing**

At initial stage respondents – PLWH applied for aid/advice to prison medical unit. Or TB was diagnosed during a scheduled examination there. But more often PLWH respondents did not apply for aid immediately. Most PLWH said that they first tried to treat their symptoms at home, and only when this did not help did they apply for medical aid. Some PLWH said that they would often take medicines for the cold or flu when they began to feel weak, and only when TB was detected through TB testing did they begin relevant treatment afterwards.

Only some respondents said that they immediately sought treatment at a medical facility. Some said that they began TB treatment only when they became clients of NGOs.

### **Tests for TB and treatment**

Respondents listed standard types of analyses for the detection of TB, particularly blood testing, fluorography, and in some cases respondents mentioned x-rays and urine testing. According to respondents, treatment for TB began almost immediately after diagnosis.

This situation is characteristic for those PLWH who were released from prison. PLWH who were diagnosed in prisons started treatment a little bit later. Some had an interval up to several months between diagnosis and actual treatment. According to respondents, treatment is provided free of charge. Family members of PLWH ensured they took their medicines on time. But these cases are rare. Some PLWH said that they preferred to get out-patient treatment as the hospital did not have appropriate conditions.

Respondents who were hospitalized said that hospitalization lasted an average 2-3 months. In rare cases hospitalization took up to 6 months. But these long periods for treatment were because the patient wanted to get treatment in a hospital, rather than in prison.

In general, PLWH assess treatment conditions as satisfactory, but some respondents still indicated many disadvantages of being hospitalized. More often this is more characteristic for respondents from the southern region.

PLWH from Kant city almost unanimously said that the attitude of medical staff is good as they think that getting complete treatment is important.

Only some respondents characterized the attitudes of doctors as formal.

Overall respondents said that the attitudes of medical staff are good.

### **Information about TB**

Respondents also mentioned their satisfaction with information obtained from doctors. Also, most respondents mentioned free access to printed information both in medical institutions, and in NGOs.

The content of talks and printed information highlight the importance and necessity of getting treatment.

Almost all respondents know about importance of taking treatment. Also they know about the necessity of following the assigned treatment regime. These conditions are necessary in order to prevent the development of drug resistance, which can result in a multi-drug-resistant type of TB (MDR-TB) and the inability to be effectively treated. All of this information was obtained as a result of discussions with doctors, knowledge acquired from printed information, participation in trainings, and consultations with NGO.

As for the question regarding completeness and continuity of treatment, it is impossible to give single definition, as some respondents try not to cease treatment. Some ceased it due to various reasons, such as adverse treatment side effects, low calorie food, business trips, etc. Some PLWH did not miss taking their medicine taking because they were very sure of its importance.

### ***Stigma and discrimination***

Most respondents do not disclose their TB status in order to avoid possible stigma. They are able to share information about their disease to close people, such as their mothers or spouses, as only they can understand and provide both material and moral support.

### ***Social support***

Almost all respondents mentioned receiving great material and moral support from NGOs.

Most respondents said that there are no problems with the surrounding people regarding one's TB status, as those who are infected with TB share their TB status only to close people and those whom they trust.

Most respondents said they obtain treatment for TB for free, and expenses are only present when traveling to a medical institution. Regular visits to medical facilities for getting necessary services are not a problem for some respondents. Almost all respondents with families said that their families provide moral support, sympathy and worry for their families.

### ***Barriers in getting treatment for TB***

In most cases PLWH respondents mentioned the lack of any barriers in getting treatment for TB. Most of them are well aware that medical staff must keep a diagnosis in confidentiality. In light of this, they did not have any fear.

Several respondents refused to answer questions regarding their HIV status. These cases were both from the northern and southern regions.

Some respondents said that they felt some prejudicial attitudes from medical staff.

In general, almost all respondents said that they were satisfied with the obtained treatment and care. The main concern is in regards to attitudes.

Respondents proposed to strengthen the nutrition in places of detention for people with TB. Also there were suggestions to improve conditions in hospitals.

## **6. Results**

### **6.1 Sex workers**

#### **6.1.1 The level of knowledge, practice and behavior related to tuberculosis and TB/HIV**

##### **Tuberculosis:**

Most of FGD participants characterized tuberculosis as a disease, which has closed and open forms.

*- It is a disease that can be of open and closed forms ...*

According to many respondents, most characteristic symptoms of TB are a cough, particularly a cough with phlegm. Other symptoms include: yellow face, chest pain, and weight loss. Some participants said that more advanced forms evoke blood spitting.

*-Cough, a person loses weight. Asthma, phlegm, lungs burning pain, chest pain, complexion of a person changes, it becomes yellow. When having advanced form- it is blood spitting...*

*-It is a disease, which causes coughing, bronchitis. When a person is sick with pleurisy and does not treat it, it can turn into TB ...*

In general, it should be noted that the information received from participants of the southern regions, is deeper and more substantial.

*-This is a parasitic disease. All people have TB germs. They are mainly located in the lungs. If a person is not treated in time for colds, flu, or neglects these diseases, a "revolution" is occurring in a human body and TB germs are beginning to devour everything. On X-ray, they are shown as white dots ...*

*-Other than that there are 120 types of TB - TB of limbs, liver, kidney, brain and so on ...  
- It is an advanced cold disease: flu, bronchitis, then a cough, if the cough persists for three weeks, and there are such symptoms such as - weight loss, appetite, body temperature is 37.38 degrees, night sweating, pallor, and blood spitting. Everything listed by me is TB...*

It should be noted that along with deep and meaningful answers of many participants, there were also those who are not aware about TB symptoms. Respondents from the Chui region said that they never had heard of such a disease.

The majority of respondents said that the main TB transmission way is through airborne droplets. Some FGD participants differentiated transmission ways depending on the form of TB, in particular where they focused on the fact that the open form of TB is transmitted mainly by airborne droplets and through the dishes.

*- If it is the open form, then through utensils, air - drop ...*

*- By household items, depending on the form ...*

*-Open form is transmitted through the air ....*

*-In a place where there is a lot of moisture, no fresh air, and if the room is not properly ventilated*

*- In one word, with no hygiene and cleanliness...*

It is necessary to pay attention to the fact that FGD participants in Osh were thoroughly discussing transmission ways. This debate demonstrated that along with the correct understanding, there were also some misconceptions, for example:

*- No, it is not transmitted through air. (Participants began discussing) If tuberculosis has been transmitted through air, everybody would have been infected. There would have been no healthy people in the world! For example, if a friend is in the TB clinic, and his relatives are visiting him ... (Osh)*

*- through kissing, sex without condom ...*

Information provided about HIV & AIDS has had an impact on the fact that some representatives of Jalal-abad city answering the question about the transmission of TB identified ways, which relate to the transmission of HIV.

*-From mother-to-child*

*-Syringe, if a group of people use one syringe or inadvertently hurt yourself by a needle...*

According to almost all FGD participants, an indifferent attitude of TB patients towards their health will inevitably lead to a fatal outcome.

*-If not treated, of course, a person will die ...*

*-Death ...*

The question on the timing of treatment of TB divided participants into two camps: those who have short-term and those who mentioned long-term time frames.

Short - term:

*-3 Months or even six months ...*

*-About six months ...*

*-at initial stage - from 2 to 3 months, and if a person is ill again, then up to 6 months ...*

Long-term:

*- 3-years or more, even during the whole life ...*

According to an absolute majority of the participants, TB is curable. Many believe that the early stage of TB, with timely medical intervention, leads to a complete recovery. However, there were such opinions that TB cannot be cured completely.

- It is not cured, it is dead-end - it is a stick, it has limited period of treatment. It is for sure. The period of treatment is long, depending on the stage ...*

Many people have profound information about behavior and practices in reducing the spread of TB. However, some respondents found it difficult to provide information on this issue.

- Food - this is important. As the human immune system becomes weak during the TB disease, you need to eat high-calorie food ...*
- To wear a mask, to follow hygiene, do not smoke, or at least smoke less ...*
- Consult with doctors more often, not to communicate with drug addicts ...*
- Try not to catch a cold ...*
- It happens that one cigarette is smoked by two or three people, and this is one of the risks of being infected by TB ...*
- It is necessary to wear a mask in that place where people are constantly coughing*
- To eat in time, to have a healthy lifestyle ...*
- For example, I try not to kiss customers on the lips. And if his appearance does not inspire the confidence of them being a healthy person, I refuse to serve such a customer ...*
- I was with him for 400 som and I will suffer for 4 years. It is better to refuse and that's all ...*
- I do not know ...*

Many respondents focused on the fact that a medical specialist must make a preventive examination. This is in order to detect this disease and start the treatment in time, which will for sure lead to effective treatment.

*- Fluorography, every six months ...*

*- It is necessary to be examined, to look after themselves ...*

*- To go to the hospital more often ...*

Also some respondents pointed out that there is a need to increase public awareness about TB.

*-It is necessary to know more about TB ...*

*-it is necessary to provide the public with information...*

Answers of respondents regarding having been examined for TB within the last 12 months were different. Many respondents pointed out that they were examined, but there were such respondents who were not examined. But the number of those who were not examined is small.

The factor or reason for being examined is a medical condition. For example, one of the girls has asthma and smokes a lot, which is why she preferred to be examined regularly and do a fluorography (Chui, west).

In general, the reasons for being examined can be classified as follows:

Symptoms:

*- I started feeling bad, and then went through all the tests, including for TB .*

The reason for not being examined for TB was due to the absence of symptoms:

*-I had no symptoms and I was not examined.*

Many girls reported that they are regularly taking examinations; some of them were last examined, on average, within the last 1-5 months.

Many respondents regularly undertook examinations, but at the same time there were such participants who, for various reasons, did not have results on hands.

*- Yes, the results are good. (A unanimous reply was received from those participants, who went through examination) (Chui, west, east)*

SWs who did not have test results explained this by saying that there was no time to go and get test results, as recently they have been working hard.

Summing up the general understanding of FGD participants about TB is the following quote. This answer reflects the completeness and thoroughness of knowledge related to TB by many FGD participants in this category, recruited into the group from pilot projects:

*There are two types of TB: open and closed. If a person has close type, it is not awful! If person takes 2 months in tuberculosis clinic and regularly takes medicines, he/she can recover quickly. If a person has open type, 100 % is that ill person will infect everybody. I think that if it is an early stage of TB and the ill person will timely apply to medical institute and will regularly take medicines, he is not dangerous for the society. If a person follows all the prescriptions of a doctor, TB is curable.*

### **6.1.2 Obstacles in applying to medical institution and getting treatment for tuberculosis**

In case of detecting symptoms of TB, all the participants agreed that it is necessary to see a doctor. But to a question “What kind of doctor to consult with?” some respondents either did not know, or named different doctors.

*- in hospital, pediatrician, to take x-rays ...*

*- a doctor, ear, nose, throat ...*

*- we have a hospital in Vorontsovka and in Bishkek near the 4th hospital. It is necessary to apply to family doctor in place of residence ...*

*- it is necessary to apply to doctors, even when a person has a cold, and if lungs chill is not fully cured, it can result in tuberculosis ...*

*-first of all it is necessary to apply to the nearest health center, if he lives in the city, and if in the village, then the village FAP and then to his closest friends, parents, family ...*

The discussion results showed that there are respondents who believe that it is useful to contact friends and relatives as well, along with doctors.

*-because in such cases, family support is very necessary ...*

*- I think that first of all you need to tell your family, then you need to go to the doctor ...*

Some participants pointed to the possibility of receiving services in non-governmental organizations:

- you can come to the office "Girlfriend" and get consultations or recommendations, you can be tested, because it is easier and cheaper ...
- to apply for aid of the Red Cross ... (Chui, west)

Then respondents were asked what places they would have applied in case of detection of symptoms of TB. There were replies regarding going to medical facilities by their place of residence:

- I went to Belovodskoe, by my place of residence...
- I, for example, went to Tokmok for full examination, by ,my place of residence ...

Some females were not able to answer (Chui, West).

It is necessary to pay attention to the fact that to some extent, the age of females determines the place they go to seek treatment. More young participants would seek help from adults. Other young females would consult with senior family members in order to protect them from possible infection.

- to my relatives, because they need to be aware, and in order not to infect them, too ....
- And, therefore, they take us to a doctor ... (Jalal-Abad)

Answers of FGD participants, which present a chain of actions, are also very interesting. This chain ultimately leads to a specialized tertiary care institution.

- it is necessary first to get a diagnosis from a doctor, and then begin treatment in a TB clinic, located in Lebedinovka ...
- you can go to a doctor at the Republican Hospital, explain what is wrong and he will send you where needed... (Chui, east)
- I would apply to the doctor by getting directions to a TB clinic, I would make x-rays, come into town and get treatment ... (Jalal-Abad)
- perhaps to the doctor - (similar uncertain response were provided by some participants) (Chui, east)

### **The main factors which prevent SWs from applying for aid and getting treatment for TB**

Participants in west Chui region unanimously mentioned the absence of factors that hinder seeking help and receiving TB treatment.

Representatives of eastern Chui oblast mentioned financial difficulties. Answers from respondents in Osh are interesting, as they identify a number of reasons that can be classified according to the following priority level:

#### Financial problems:

- Finances and shame are the main factors. Finance - because the examination and treatment for TB costs a lot of money. Shame, because those who were there saw us and can spread rumors that I am "ill with TB" ...

It was indicated, that only specialized hospitals perform examinations.

- Other hospitals do not accept people with TB ... (Jalal-abad)

#### The lack of places:

- Due to the lack of places and beds, TB clinics do not accept ill people .
- Doctors do not examine referring to the lack of beds in hospital

#### The lack of identity documents:

- if a TB patient has no identification documents, passports .

### Cynical doctors:

- there are such doctors who look and say - *Go! You're already going to die!*
- doctors also say, *"You've got 10 days to live, you came late, a disease is neglected ..."* (Jalal-abad)

### Stigma:

- conviction ...
- attitudes of doctors to patients must be improved, and after being hospitalized medical staff and doctors are doing their work as "excellent" ... (Jalal-abad)

### Possible stigma (or fear of possible stigma) is a significant barrier to getting treatment for TB.

- people hear that you have TB and begin to separate them from you... Sometimes it can be seen when you get out of a TB prophylactic center, so you need to bring to the people that no one is protected from TB, even from any other diseases ...
- there is a need for individual approaches to TB patients and doctors in FGP should also keep everything in confidentiality. And there is that the house of TB patients will be disinfected by sanitary station of people in suits. I think you cannot do it, because neighbors can blame them...

Some participants found it difficult to answer this question. (Chui, east) Some females from Osh listed the risks of losing clients as the main barriers for getting treatment in a medical institution.

- the possibility of losing clients. Health does not allow me to work outside, and there are no finances to treat it. TB - it's not the flu, which allows you to return to work in 3 days ...

In the Chui oblast, all the participants unanimously said that it is an opportunity for **self-applying** to medical institutions for getting treatment for TB.

- I need my health, right? If I do not take care of my own health, who will help me? No one! And while we are healthy we have clients, we work, communicate, and live.
- If we risk our health in relation to such diseases, we will feel bad.

As for the southern region, the possibility of **self-applying** is not for everyone. Respondents pointed towards TB-related and SW-related stigma as the main reason.

- First, it is shame. Second, if usual person has broken hands, doctors cannot properly take care of the sick. But in addition, we - SW with TB!
- It seems to me that there will be not good attitude...

**Moderator's comment:** As for this issue, opinions of groups differ, half of the participants stated that attitudes of the medical staff are good, but others argued that the attitudes of medical personnel to SWs must be improved.

- We get consultations, then what we do not know, we can ask from doctors, i.e, in a word, they are working well ... (Osh)

It was mentioned that amicable attitudes to SWs are only present when SWs are accompanied by representatives of NGOs since they are partnered with NGOs.

- Not long ago, Mavlyuda (worker of "Girlfriend" office), took us to be tested, we were not treated badly, we were treated well, we were provided with recommendations. I did not notice any bad attitudes towards me...

During focus group discussions in Osh, participants asked to take care of the issue of medical staff refusing to take their analysis.

*-After 3 months of examinations and after receiving treatment and injections, doctors do not take our analysis. I do not know why. Can you solve this issue? Please make a note of this ...*

Opinions of participants regarding treatment and care for TB indicate that in general there are no problems in relationships with doctors.

*-There were no problems in getting treatment, they treated us very well ... (Chui, west)*  
*- I know little about treatment because a person close to me is sick with this disease. We went to a doctor, he was diagnosed and hospitalized, we bought medicines using our own money, but not all the medicines, but only those which were not in the hospital. There were no expensive medicines in the hospital. But in principle, treatment is so-so ... (Chui, east)*

There were individual statements about misdiagnosis, which led to some emotional discomfort.

*- I was feeling bad, I went to a doctor, the symptoms were similar to tuberculosis and I was hospitalized, where there were 6 people with tuberculosis, after X-rays on Monday, I was diagnosed that I had pleurisy of the left lung. You see, all this time I was lying with the sick, and was so upset that I became thinner. I was so much mentally damaged because of this incorrect diagnosis, so that the treatment is so-so ... (Chui, east)*

There were also signs that doctors practice collection of informal fees.

*-Attitudes of doctors to patients is prejudicial, if you give money, you are well treated, if not, they do not even see you... (Chui, east)*

Some females have a sustainable thinking that there is a need to take care of one's own health, specifically to ensure that their bad health doesn't become an obstacle for the success of their career..

*-Our job requires it, our earnings depend on our health ...*  
*-We can infect customers, and they can infect other people, if it turns out that we could be sued...*

### **Awareness about HIV**

If this issue is considered in view of places for services rendering, participants from the southern region are well aware of it, whereas, representatives from Chui oblast have more general information.

#### Sokuluk; Shopokov, Kant

*-It is an infection ...*  
*-Infection ...*  
*- It is a disease ... (Multiple answers)*  
*-Also answers: we heard, but I do not know ...*

#### Kant

*-It is a disease, but what disease I do not know*  
*-This is a virus ...*  
*-The virus, which is not detected for a long time, and AIDS is the disease itself ...*  
*-Transmitted diseases, sexual contact ...*  
*-Human Immunodeficiency Virus ...*  
*-This is a sexually transmitted infection ... AIDS, syphilis ...*

*-This is a contagious intimate disease...*

### Osh

*-This is an infection that destroys the body's immune cells. The human immunodeficiency virus ...*

*-Viruses, that are found in human blood and through the body ...*

### Jalal-abad

*-HIV - infection, infectious disease, which is transmitted from mother to child, through blood, through a syringe ...*

Many females showed a quite correct and complete knowledge about the transmission of HIV:

*-Sexual way ...*

*-Through the blood ...*

*-Breastfeeding, syringes ...*

*-Through sexual contact, genital discharge, milk, during pregnancy, from mother to child, through blood ...*

*-From mother to child, through a syringe, blood, sexual contact. When talking, through the blood, and through a syringe, through a manicure, pedicure ...*

There was such a case in Shopokov city, Chui oblast, where a razor was named as a transmission way.

*- A razor, for example, my father is ill, and his son shaved, he can also get sick ...*

There were also responses that indicate a distorted view of how HIV is transmitted.

*- Through the air ...*

*- Saliva ...*

*-A handshake ... (Kant)*

**Moderator's comment:** One female said that HIV is transmitted through shaking hands. It caused numerous protests from other participants of the group. To which she responded, that she was wrong, and said that HIV is transmitted through the air and saliva ... (Chui, east).

Answers to the question on how HIV is not transmitted, revealed SWs' precise understanding of HIV transmission.

*-Through utensils, hugging, shaking hands ...*

*- Across the pond, a kiss ...*

*- I do not know ...*

*- Saliva, when communicating;*

*- A handshake;*

*- In a public bath;*

*- While communicating, kissing;*

*- Through air;*

*- Dishes, hugging, and clothing.*

*-Handshake, use of utensils, i.e, not in the body - outside the virus dies immediately....*

*-When communicating, sharing food, through clothing. In the air, the virus dies...*

**Moderator's comment:** The most active participants gave answers immediately, others responded by leading questions, which was common in Kant.

Many females think that HIV testing is the only way of detecting HIV.

- *Yes, the only way (most of the answers) ... (Osh)*
- *Blood tests, the only ...*
- Yes, only an HIV test ...*
- *Only an HIV test can detect HIV infection in the body. Blood test, and so you can find out ...*

However, there were opinions that there are many other ways of transmitting HIV. But when they were asked to list other ways, they could not name them.

A person who looks healthy can have HIV, this opinion is shared by all females.

- *Even a person himself does not know that he is sick, apparently it does not manifest itself .... (Chui, west)*

Why?

- *It is because the virus is inside the body, it can be detected only through blood, and it looks as usual, as always ...*
- *Because he (man) cannot know how and where he was infected. Maybe it was through a dentist, hairdresser, through manicure - pedicure. If inadvertently infected blood got into his blood, through sexual contact, isolation ...*
- *"yes"! The virus can be detected not immediately, but after a certain period, and then when he or she gives blood for analysis*

### **Frequency of taking HIV test**

The opinions on the frequency of HIV testing is different and of a wide variety. The exception of this was FGD participants from Jalal-abad, as they unanimously agreed that there is a need to be tested for HIV every three months.

#### Chui, West

- *every six months;*
- *every three months;*
- *2 times a year;*
- *There is a window period, so every three months;*
- *Two or three times a year, every six months;*
- *Every month;*
- *Do not know.*

#### Chui, East

- *Once a month, because my work requires it (4 responses);*
- *Once every three months, (2 answers);*
- *Once a year;*
- *In six months time;*
- *2 times a month;*
- *Three times a month.*

#### Osh

- *Once in three months ...*
- *Every 6 months ...*
- *Once in 9 months ...*

The last time the respondent tested for HIV:

- *I had my blood tested 3-4 months ago ...*
- *Half a year ago...*
- *At the end of May (also 3-4 months ...)*
- *2 months ago ...*
- *A week ago ....*
- *Month and a half ago ...*
- *Did not test ...*
- *Three months ago ...*
- *20 days ago, came and tested blood ...*
- *2 months ago ...*
- *2 months ago...*
- *A week ago...*

All participants in Jalal-abad, said "a month ago."

Some participants tested a while ago and it was difficult for them to say when exactly they tested (Chui, west).

All SW respondents who said they went through testing got their test results.

- *Yes, I have, they called and said that the result is negative;*
- *I called, they told me to call on Monday;*
- *I passed the medical tests in CAIS + and received my results.*

Reasons for not receiving test results are as follows:

- *I did not get it, because if the result is negative, they do not call ...*
- *There was no time ... (Osh)*

### **Awareness about ARV therapy**

All participants of the Chui oblast did not know about ARV therapy. In contrast, the results show that participants from the southern region are more informed.

- *There are pills that help prolong the lives of HIV positive people. Because HIV positive are more committed to other diseases and HIV in the body occurs and causes other diseases. Therefore, HIV positive people are prescribed with ARV therapy. (Osh)*
- *Treatment, which improves, i.e. supports the immune cells...*
- *Treatment prescribed by a doctor to people living with HIV if he is infected with HIV and his immunity is "devoured" by the virus ....*
- *Pills which need to be taken in a timely manner. If you do not follow regime for accepting these pills, there is no effect, there will be no results ....*
- *That's right, if the regime is not followed, the immune cells, i.e. indicators may be reduced. (Jalal-Abad)*

### **Awareness about commitment to ARV therapy**

Awareness of adherence to ARV therapy, as well as awareness about ARV, is low in surveyed cities of the Chui oblast. Almost all respondents answered "do not know". Some awareness was noticed in the surveyed cities of the south region of the country. According to their replies, adherence means strictly following the regime and taking the pills in the correct manner.

- *To take pills timely. Day to day, hour to hour. If you forget, then you will need to restart. (Osh)*

*-If it is prescribed, take it morning at 8 o'clock and 8 o'clock in the evening, and then you need to take these pills. If not, the immunity may diminish ... (Jalal-Abad)*

### **Awareness about AIDS**

Representatives of Chui oblast showed some limited awareness about AIDS.

- Infection of blood ...*
- A man is sick with an incurable disease ...*
- This is a disease that can develop very slowly, it is not detected immediately. My friend was sick, we found it out in 1.5 years ...*

Moderator comments: To the question: How is each letter in the word AIDS is decoded? – no participant provided a full answer (Chui, west).

The situation in this issue is a little bit better among participants from Kant city.

- Virus ...*
- Immune Deficiency Syndrome ...*
- This is an incurable disease ...*
- It occurs in 6 months and if left untreated - a person can die ...*
- This disease is sexually transmitted ...*
- This disease shows itself in 5 years ...*
- At the initial stage of AIDS, a person loses their hair and there are all sorts of body ailments ...*

Some females have heard and know of the existence of such a disease, but cannot say what disease it is. But these are only rare cases (Chui, east).

If compared with Chui oblast, the situation in the southern regions of the country is a little bit better.

- it is the last stage of HIV. Acquired immunodeficiency syndrome.*
- a person does not have immune cells. (Osh)*
- it is a disease, where HIV becomes AIDS. It can be transmitted through sexual contact, in this case, and if the sexual contact is without "condom" ... (Jalal-Abad)*

### **Awareness about combined infection – TB/HIV**

As for this issue, most females answered – do not know. (Chui, West, East).

- I do not know ...*
- Also it depends on blood, tuberculosis is also transmitted by blood ...*

Moreover, respondents mentioned the seemingly incompatibility of the two diseases.

- Two different diseases, which, in my opinion, are not compatible ....*
- One person cannot have tuberculosis and HIV (Chui, east)*

The situation in southern regions shows more correct awareness.

- they are parallel ... HIV infection in blood, TB in lungs ...*
- those who have HIV can be easily infected with TB (Osh)*
- the majority of TB patients cannot be infected with HIV if they lead a healthy lifestyle, i.e., are not drug addicts and so on. If a person is infected with HIV, there is a 90% chance of having TB. Because the immune system in HIV-infected people is too weak and he can*

*easily be infected with such diseases as TB, diabetes, Botkin.  
- HIV - like adhesive paper, it sticks everything. Or, like a sponge. (Jalal-Abad)*

As for the question regarding the impact that HIV infection has on being infected with TB, **most females** said - I do not know, particularly in the western part of Chui oblast. The responses provided were rather vague and not specific,

- *Immunity of a person is weak...*
- *Of course, it will worsen, a person is ill with AIDS and tuberculosis...*
- *Probably a very bad influence*

According to FGD participants in Kant city, TB coupled with HIV infection will inevitably lead to a lethal outcome.

- *It is bad, because these are both difficult diseases ...*
- *Immunity vanishes, and if there is TB, a person will die ...*
- *The organism is not capable of struggling with the disease; naturally the person will die ...*
- *Complication, weakness...*
- *The person is weaker, than the general population ...*
- *Such a person will die ...*
- *In general in Kyrgyzstan it is rare to have people living with AIDS and to have people with both AIDS and tuberculosis.*

(Chui, East)

In Kant, Shopokov city, Sokuluk **most** respondents answered – do not know...

- *Tuberculosis progresses, hair starts dropping ... (Osh)*
- *If a person has only TB, it is already so difficult, and it is much more difficult, when a person has HIV and TB,*
- *It is difficult for the organism to struggle with two infections ...*
- *Likely, TB progresses much faster ...*
- *it is difficult, probably*

(Jalal-abad)

### **Detection of TB in people living with HIV**

Opinions of respondents on methods of revealing TB at PLWH can be classified in two groups:

1. On external symptoms
2. Through testing
  - *Spitting, also phlegm ...*
  - *The person becomes pale ... a person sleeps badly.*
  - *It can be seen, as always (blood testing), it is necessary to be examined...*
  - *Through analysis, X-ray, through phlegm and external signs ...*

**The greatest quantity** of representatives of the Chui region were not able to answer.

Also participants said that PLWH discovering that they are infected with TB does not differ members of the general population discovering that they have TB.

- *Cough is the same, symptoms are the same...*
- *The same way as members of the general population discover that they have TB ...*
- *PLWH have the same symptoms of TB as usual TB people...*

### **Treatment of TB in PLWH**

Most respondents from the west Chui oblast do not know about the treatment of TB in PLWH. Only an insignificant part tried to answer, but answers were uncertain.

- *As usual but the disease is difficult because of weakened immunity*

- Immune system is weak...
- Also antibiotics, pills ...
- Injections and I do not know ...
- Simultaneously, likely ...
- No, it is impossible to treat simultaneously; medicines can give a side-effect, in the beginning it is necessary to treat for TB, and to take HIV pills after being treated for TB...
- In parallel ...
- No if he is not prescribed with ARV therapy, it is possible to be treated for both diseases, but before being prescribed with ARV, it is necessary to be treated for TB ...

Almost all respondents pointed out an importance of treatment adherence in order to be cured of TB. First of all, in their opinion, adherence is important for their health, prolongation of a life and an exception of epidemics among the surrounding people.

- In order to not to spread it, to think not only of yourself, but also about your surrounding people and relatives ...
- To live longer ...
- For the sake of health ...
- Tuberculosis is such an illness, it progresses very quickly, a person is infected by it because of weakened organism, and therefore it is necessary to be regularly examined ...
- In order not to die ...
- It is obligatory to be healthy and to know, that you are threatened by nothing ...
- First of all, for health ...
- It is important! Consequences can be pity ....
- The patient can infect the surrounding people, friends and society ...
- A person can die from TB ...
- TB does not wait for treatment to begin, TB will start and when ill person will take pills. It will just destroy the lungs of a person, which can lead to death.

### **6.1.3 Motivation for applying for and getting treatment for TB**

The main reasons for applying to a doctor for starting treatment are:

1. awareness of the value of health:
  - Self-preservation...
  - We immediately applied to a doctor, we did not need any motivation ...
  - At this moment you do not think about motivation, you just run to the doctor yourself ...
  - Each road has its own life, so maybe ...
  - The desire to be cured of TB ...
2. care of close people and relatives:
  - children, parents and their health...
  - support of close people...

All FGD participants indicated at the importance of their own health.

- Very important. This is important in life ...
- We have health, then we live ...
- If you are ill, you will not get married or family may be destroyed ... (Osh)
- like air ...
- like life, like a child ...
- as the belief that you'll be fine ...
- as water, bread ... (Jalal-Abad)

Many FGD participants highlighted the importance of moral support from family, friends and some pointed to the usefulness of support from doctors. Some also noted the need for financial support.

- *Moral support from the family ...*
- *Any kind of support ...*
- *All existing support, especially support from relatives ...*
- *All the support and financial support, particularly ...*
- *first of all - a doctor's support, secondly, financial support and support of relatives ...*
- *Support from doctors, if the person who knows your body completely and what is going on these, you will quickly get over the barriers...*

#### **6.1.4 Stigmatization**

Answers to the question of who and what kind of people can get TB, can be divided into the following groups:

1) People who are living in unfavorable living conditions, and 2) people who have bad health habits, and 3) no one is safe from getting TB.

- *Those who live in damp places ...*
- *Mainly people, who are in prisons, who are ill ...*
- *The homeless, drug addicts, and ordinary people, too ....*
- *People who live in damp places, in the basement ....*
- *Dust, dirt, smoke ...*
- *All people can get sick ...*
- *Smokers, drinkers ...*
- *People who do not observe hygiene ...*
- *People having farms with cattle, because they can become infected and the cattle too....*

- *Everyone can have TB! But we – SWs, drug addicts, smokers, prisoners, poor families, where there is no good food, are most at-risk...*

The reasons for having TB are also associated with poor living conditions, alcohol consumption and smoking, as well as having a bad attitude towards health.

- *When people smoke a lot ...*
- *Do not look after their health ...*
- *Do not go to the doctor, often get cold ...*
- *Do not dressed warmly, do not take care of themselves ...*
- *Malnourished, weak immune system ...*
- *If you do not look after yourself (in terms of health), you will get sick ...*
- *Do not treat fully a chill;*
- *They live in damp ...*
- *in our case, if we kissed people with TB, we can be infected through saliva ...*
- *no information ...*
- *they look at their health with blind eyes ...*
- *maybe people live in poverty, low income families ...*

In general, attitudes of respondents to TB people are quite loyal. They are more likely to treat them with understanding, to some extent, with a touch of compassion.

- *To assist and support such people ...*
- *Nobody is insured, so we need to be sensitive to these people ...*
- *Pity cause and compassion ...*
- *Treat as well as to normal people ...*
- *I wish they quickly recovered ...*
- *Do not think, to be honest ...*

- *nothing, they are the same people like we are ...*
- *nothing wrong with that! God, what if we ourselves were in their position...*
- *as people say, "Do not judge, you will not be judged" ...*

Many respondents in their lives met and were in contact with TB patients, and many had TB patients who were their close relatives. Respondents from the southern region mentioned the following:

- *Yes, I know some TB patients ...*
- *Yes, my loved one had this disease ...*
- *Yes, there is a friend, he was in the TB clinic in Vorontsovka, we visited him, he was treated for six months as it should be ...*
- *Yes, we know, my uncle died of TB ...*
- *my brother was treated for TB ...*
- *neighbors, friends ...*
- *we know some...*
- *yes, of course! My uncle died of TB. He was in prison, and there it is not treated, he was released and died a month later. It was terrible to watch, thin, bluish face ...*
- *My mother is ill at the moment ...*
- *my classmate has TB, nobody communicates with her in our village, all have turned away from their families, and villagers and their relatives. Even her friends treat her with disgust, when she wanted to greet with them ....*
- *each of us has family members and friends who are ill or suffer from TB ..*

The vast majority of participants would continue being in contact with TB patients. Some would maintain relations indirectly, such as by the telephone. Among respondents there were some (a minority) who would stop communication. This was rare.

- *Yes, we communicate now as we have done earlier ...*
- *We continue to be friends, because she recovered ...*
- *Yes, of course. It is certain that they need to be provided with assistance. We need to see how quickly he will be cured from this disease ...*
- *Yes, I continue, I have been living with this person for my whole life ...*
- *I do not have such friends, but if I did, I would still communicate with them, they are normal people ...*
- *probably only by phone - If a person has an open type of TB, then no, I would not talk to them, even after treatment ...*

### **Information about TB**

Respondents mentioned the need for information about TB. Representatives of the Chui region would like to get full information about TB.

- *Full information about this disease ...*
- *All the information from A to Z.*
- *More life stories of TB patients or former patients ...*
- *About new medicines ...*
- *What I know seems enough ...*

The respondents prefer to get this information in Russian and Kyrgyz. Discussions were named as forms of getting information, as they help to gain clarifications. Printed media, video, and disks were also in demand.

- *Magazines and videos ...*
- *It would be very interesting and useful to have a specialist come and tell everything about the disease. It is impossible to ask what interests you when you watch a TV-program. When watching a disk, for example, there are a lot of questions that arise, and*

*it turns into communication, but one-sided.*

- *I do not care what kind of information it would be, I am interesting in everything ...*
- *Magazine, which I can always read during my spare time ...*
- *conversation, TV programs, leaflets in Kyrgyz ...*
- *special TV programs, mostly broadcasted after 10 am and to 18 pm ...*

According to discussion results, the respondents had no other additions to the questions. And none of them were migrants, but, in fact, it was possible to understand that basically, all the participants are internal migrants, who come from villages. Of all respondents, only 3 participants regularly travel abroad for work. HIV tests were passed by them in the country in which they work.

- *I was in Turkey and went. I go, pay myself and pass test for myself. In Turkey, nobody force you to take a test, it is on your own desire...*
- *I pass the test, where I work. When I want, for myself ....*
- *I was tested in the airport of Dubai, doctors themselves came, took tests ... very quickly and in 5 minutes give results ... (Chui, east)*

The reason for being tested is, in particular, care about one's own health:

- *Because I worked there for 7 months, it was necessary to be tested, there nobody is taking care of your health ...*
- *For your health ...*
- *Live there, work there, that is why I was tested there ...*

There were barriers for getting tested for HIV. Also, some females sometimes advise their clients to be tested for HIV.

## **6.2 People who inject drugs**

### **6.2.1 The level of knowledge, practice and behavior related to tuberculosis and TB/HIV**

#### **Tuberculosis**

**People who inject drugs (PWID)** respondents, regardless of the regions, showed a deep knowledge about TB. This is indicated by the thoroughness and completeness of their responses. Besides symptoms, transmission ways were listed. Most of the participants named common symptoms of TB and added TB transmission ways.

- *weakness, sweating, spitting, phlegm...*
  - *Cough, fever ...*
  - *Weight loss ...*
  - *shortness of breath, loss of appetite ...*
  - *Pulmonary disease ...*
  - *TB, in my opinion, is transmitted by airborne droplets, if the cough is more than for 3 weeks and there are temperature and heat, it means that it is necessary to see a doctor...*
- *temperature, weight loss, sweating, loss of appetite, blood spitting, frequent and short cough. Weakness, fatigue, especially at night, sweating, pale skin, hair loss, shortness of breath, chest pain...*
- *Well, by using single dishes ...*

While considering the main TB transmission ways, the respondents tried to differentiate its spread by forms. Mainly airborne transmission way was specified.

- *Airborne droplets*
- *if it is of open, then through air ...*

- Saliva...
- Through blood ...
- Cough ...
- Basically, indoor ...
- Well, people are mostly infected when there is humidity, there are too many infected when living together ...
- When tuberculosis is of open type, it is transmitted through dishes, and by shaking hands and so on ...
- Well, if a person is sweaty, has sweaty hands, you smoke his cigarette, in this case you can be infected as well...
- In a bus, where there are a lot of people ...
- Cough (indoors). When he (TB ill person) coughed on you ...
- You can become infected if there is a TB patient and he coughs and sneezes, and the room is not ventilated. There is infection in it ...

According to most respondents, in the case of a neglected/ advanced disease, a person will die.

- A person can die ...
- Over time, there are holes, a person spits his lungs...
- Over time, your lungs became worse, you spit them ...
- A person loses weight ...
- If he is not provided with timely care, of course, he dies ...

Many listed the following TB symptoms.

- impaired respiratory system, lungs, immune system suffers ...

According to respondents, the treatment period depends on the TB stage. Of the views expressed, we can see that shorter time is required for an early stage, and more for the second stage, which can take one or more years. The discussion in regards to the period of treatment revealed some controversial points among PWID, which indicates that the respondents do not have uniform information about it.

- minimum of 6-8 months, maximum 2 years ...
- At the first stage – up to one year, with the second stage - up to two years and this is a very expensive treatment ...
- Two - three months in the hospital, and then out-patient treatment, a person is sent home on a maintenance phase ...
- Four to six months ...
- Quickly. One week and that is all ...
- Ten years can be not enough to treat it ...
- A person can live for 20-30 years with TB, and even more and not to cure ...
- From 9 months to 2 years ...

Respondents were arguing.

- At the initial stage of TB, treatment takes 2 months, and if the result is not good, in this case treatment lasts from 9 months to 2 years, but occasionally the patient should be under medical supervision. If the patient interrupts treatment ...
- At initial stage, he will have medicine resistance, and then he will need to take more powerful medicines ...
- TB can be of closed and open forms. If TB is detected, a person is “closed” in the hospital. After recovery, the patient may get outpatient treatment at home. But he must constantly be observed by a doctor and consult...

All FGD participants agreed that TB is curable, but it depends on the stage of the disease and proper approach to treatment, which is largely determined by the responsibility and

consciousness of the patient. There were also opinions that indicate some awareness of respondents about resistant TB.

- *At the first stage, it is curable ...*
- *the last stage of TB also curable, but it is very difficult ...*
- *At the first stage the body gets used to one medicine, and other medicines do not help, in this case the doctor prescribes other medicines ... and treatment is extended to two years ... (Bishkek)*
- *It is curable, only if a person applies to a doctor in time, and depending on the stage ...*
- *Now, there is "Red Cross", treatment is provided in camps, they cure ... there are all sorts of medicines in the camps....*

Some believe that the resistant form cannot be treated at all or is difficult to treat.

- *No, it cannot be cured, it can be only deadened...*
- *When it is already neglected, then decay started. I think nothing can stop ...*
- *No decay, there are resistant forms. Stable form is poorly controlled ...*

There were such opinions that TB cannot be cured completely, and that you can only "deadened" it when using the right health-related. The life period and quality of life depend on the patient.

- *Yes, it's an infection, there are ulcers. Ulcers multiply ....*
- *No immune system, a person does not recover ...*

Respondents are well aware of the measures that prevent the spread of TB. In general, all measures listed can be classified as follows:

Apply to a doctor when seeing initial symptoms:

- *First, it is necessary to see a doctor, try to limit contact with people in order not to infect them...*

Preventive measures:

- *To make fluorography once a year ...*
- *Personal hygiene...*

Safeguards:

- *if a person knows that someone has TB, he must wear a mask, you must use a scarf ...*
- *If you know that a person is 100% ill with TB, a person does not need to communicate with him. It is desirable to stand downwind, the wind is blowing away from me for it and use separate plates and cups and personal belongings ...*
- *To ventilate facilities ...*
- *Often sanitize ...*
- *must follow hygiene ...*
- *If a person is ill with TB, he should wear a mask in public places, he should at least use a handkerchief...*

Limitation of bad habits:

- *It is necessary to stop smoking...*

Informing the surrounding people:

- *And immediately inform relatives, in order they do not live in the same room....*
- *If you know about TB, you need to inform the surrounding people. If a person coughs in a room, and in order not to hurt him, you just have to ask if you can open the window, or to say that it is stuffy, ventilate the room, you need to carefully treat all ... to do wet-cleaning in a room, houses, etc. You can chat with your friends, they can be informed about TB, and they will inform the other...*

All participants were screened for TB within the past 12 months. All participants of Osh city said that they test for TB 2 times a year.

All participants received results. Outreach workers often take responsibility on this over themselves. Also, the doctors register and communicate with patients.

### **Time, place and reasons for applying for medical aid**

The range of treatment sites where a person can apply when detecting TB symptoms is not wide. Most often, these treatment sites are either a medical institution or a non-governmental organization.

- *In a narcological dispenser...*
- *We are from the "society" and we pass all the tests, give our phone records and if the result is positive, you will be called, and if the result is negative, a doctor will not call you ...*
- *We go to a TB clinic with a social worker and immediately get results - in half an hour, if a person is ill with TB, they help with treatment ...*
- *In FMC, to apply to hospitals, to their family doctor or TB doctors there ...*
- *outreach workers, who can accompany you...*

Cases of non-traditional measures of treatment were listed.

- *We went to Koreans to get dogs ...*

### **6.2.2 Obstacles for applying to medical institutions and getting treatment for tuberculosis**

PWID respondents mentioned a lack of clear-cut barriers in getting medical care. Some mentioned certain stigma and financial difficulties.

#### Lack of barriers

- *No, as we know about TB symptoms, and immediately apply to "Plus center", where we can be provided with support ...*

#### Lack of finances

- *lack of money, because if you go without accompaniment, the X-ray costs 120-140 som ... (Osh)*
- *The first thing is financial, sometimes, they write you a list (list of medicines), oh-oh ... And we do not have finances to buy them...*

#### Stigmatization

- *Somebody is shy or thinks that their relative will find out about it.*
- *Large publicity ...*
- *Well, here you can see, if we consult with an outreach workers, we already know that it's all anonymous, only he will know, and the doctor will know it ...*
- *the outreach worker will take you for free, even he will pay for your travel in order not to spread this infection....*

Some respondents listed the lack of required information as the main barrier.

- *if you are not informed, what will you do?*

This issue was subjected to intense discussion among respondents, using examples on how people usually behave in this case. According to them, people self-treat at home, take antibiotics, do traditional treatment, and when there is no improvement, they go to a hospital, take direction and are treated. According to them, having heard of the diagnosis, people "close themselves", being afraid of infecting others, having shame. This then first leads to the infection of their families, and ultimately results in complications and neglect of the disease.

- *we are informed and if we feel or see symptoms of TB, we immediately come to the "Plus" center! You should get support and start treatment ... and those who do not know it is self- treatment ...*

### Self-treatment

To some extent, relying on self-treatment in early stages of symptoms' development is a barrier to getting skilled medical assistance. Non-traditional treatment methods, such as eating dog meat and fat were listed.

- *At least peoples' methods ...*
- *dog meat helps ...*
- *Yes, not meat, but fat ...*
- *Yes, fat of a dog ...*
- *Milk, honey ...*
- *Milk, honey, yes ...*

Many respondents do not experience any barriers in getting treatment when seeking medical care. Except some moments, when the reason is the lack of documents.

- *personally for me it was problematic, I do not have passport ...*

Many respondents still indicate that accompaniment by a social worker or an outreach worker enormously facilitates the process.

- *It is much difficult to go yourself ...*
- *Yes, it is harder...*
- *And many do not know where to apply here*
- *There would be a delay and that is all ...*
- *I can go to my own clinic, but as it was said here, there is always such policies at clinics "go there, bring It". Therefore, I find it easier to apply to the "Plus center." Here the guys are experts and they can help quickly. They accompany and everything is resolved quickly ...*
- *Or, if there is no social employee, you can get directions with stamp of the organization and go through examination...*
- *and also the reason for applying to the "Plus" center" is that someone does not have money, X-ray costs 120 soms. After receiving a referral from "Plus center" we can get the X-ray for free....*

PWID respondents mentioned not having any problems regarding applying for and getting treatment for TB.

- *They quickly give results ...*
- *We are taken without staying in a queue, if there are 5 people, a doctor leaves the main queue, and takes us because we're from society ...*
- *yes, even if we turn to the clinic alone, we will have to pay, but when we apply to "Plus" center they provide direction to us, and we get free treatment. Because the staff of "Plus" center knows all the details, and of course the staff of "Plus" center knows all the doctors, and it is easier to obtain medical services...*

However, some issues are not affected even if you are accompanied by outreach worker:-  
*medicines, bed, pajamas, food, x-rays, care, bypassing, analyzes ...*

### **Awareness about HIV**

PWID respondents are aware of HIV:

- *sexually transmitted disease, nothing good, the whole body is infected, it is worse than TB, TB is curable, but AIDS is not, I did not hear that somebody recovered from AIDS ...*
- *A virus...*
- *It attacks the immune system ...*
- *there is a window period, you can test blood, you may already be infected with, but the result will be negative when HIV is not shown, that is, one can further infect anyone - ever. After six months should get tested again*

*The human immunodeficiency virus is transmitted only in three ways: through blood, sexual contact and through the mother's milk. It is not transmitted through a handshake, communication, through dishes, etc. (Osh)*

There were the following replies as well:

*Even when one person has pricked himself by a thorn, and if the other person will stay on this thorn, he can be infected as well...*

To the question on how HIV is transmitted, the following answers were received:

*- Through the air, and it is not transmitted by the usual way, and it is also not transmitted when a mosquito or animal bites....*

*- A kiss and utensils, it is not transmitted through a handshake ...*

*- In the pool ...*

*-It is not transmitted in everyday life ...*

*-a towel ....*

*-Even not through washcloth...*

*- Well, a person can share a bathroom, dishes, and he will not get infected ...*

According to majority of respondents, a HIV test is the only way for HIV detection.

*-yes, a HIV test is the only method (unanimous answer)*

A unanimous reply was received that a person, who looks well, can have HIV.

Opinions of PWID respondents regarding the frequency of being examined for HIV was shared as follows:

1. Regular testing within a certain time interval:

*-once in three months...*

*-every six months...*

2. After risky case:

*- I think in general, after you, for example, had a sexual relationship where condoms were not used and if you are not confident in your partner, feel free to go get checked, casual sex can also lead to infection ...*

Respondents also provided information regarding window periods.

*- The "window period" - let's say is when the person is injected or was with a partner, who are already infected with HIV, but you are tested and the result is negative, but in six months it might be HIV ... (Bishkek)*

Answers that contain regular time intervals in which the participants have to be tested for HIV also show a high awareness, as the respondents in this category belong to a group who have a high risk of being infected. So a regular HIV test will truly inform about one's status.

*- No, it all depends on his lifestyle. If I'm a drug addict, I need to be tested every day. And if I had one sexual partner, then why should I get tested every three months ...*

*- even if a person is tested every day – it will not give anything, because the "window period" can detect the presence of HIV infection ...*

**Period of last HIV testing**

6 PWID respondents passed a HIV test -4 months ago, 4 PWID respondents-1 month ago, 5 months ago (Bishkek)

3 respondents passed a HIV test -2 months ago, two respondents -1, 5 months ago, 3 respondents - 1 month ago, 2 respondents – one week ago (Osh).

All participants received their test results. Also, many noted that the availability of information on HIV provides an opportunity to adequately assess and receive data about test results.

*-we possess information, which is why we calmly treat this information...*

### **Awareness of ARV therapy**

In general, respondents are aware of ARV therapy. Almost all respondents are aware of the fact that this treatment is accompanied by strict adherence/commitment to the regime.

- *it is the treatment ...*
- *who is sick with HIV, it (ARV) prolongs life ...*
- *it is supportive therapy in order not to get AIDS ...*

Also many respondents compared ARV therapy with the level of diabetes cells in a body.

- *those who have diabetes cells level - 350, they are prescribed to the ARV therapy. A person takes it three times a day ...*
- *it is a pill that must be taken three times a day, preferably at the same time ... (Osh)*
- *CD4 cells; to make sure they are at a sufficiently high level, the norm- 800-900 for a normal person is admissible, if you have HIV it progresses from 200 to 250. Then a person needs go through antiretroviral therapy ... (Bishkek )*
- *If a critical condition of these cells is there, the doctor prescribes it ...*

Respondents are also aware of the importance of adhering to ARV therapy.

- *Adherence to ARV therapy means timely acceptance of pills within an hour. You cannot take them before or after the specified time, three times a day. (Osh)*
- *Say, if a person already has antiretroviral therapy - it must be taken constantly at one and the same time each day, if a person forgets it, even these pills will not help...*

### **Awareness about AIDS**

All respondents without exception can decode this abbreviation. Many respondents, talking about AIDS, pointed out that this is the stage after HIV, and also named the distinctive moments of these two stages.

- *The last stage of the disease ...*
- *HIV - infection, AIDS is a disease ...*
- *HIV - the initial stage, AIDS is the disease specifically ...*
- *This is the stage after HIV ... The last stage, as well as in tuberculosis ...*
- *Incurable ...*
- *No HIV but AIDS is all this already infected ...*
- *This is the end, this is a disease ...*

Most PWID noted the availability of a regularly increased temperature.

- *A person, who has a constant temperature has AIDS ...*
- *This constant temperature is not reduced ...*

Respondents indicated at the irreversibility of processes in a body.

- *Those who have AIDS do not recover, if a person has a chill, it will not be cured ...*
- *The body is not struggling with this disease ...*
- *The organism does not fight, tuberculosis begins there ...*
- *Well, I guess when a person has AIDS, he will not recover, he did not treated,...*
- *A person can die (from various diseases) ...*

### **Awareness about combined infection – TB/HIV**

These respondents possessed information about HIV / TB co-infection. Many had a quite correct understanding of the interaction between the two diseases, and knew that TB is a major concomitant disease in HIV.

- *They are always together ...*
- *Two boots - a pair (TB / HIV) ...*
- *Two diseases in one body ...*
- *Opportunist, so to speak ...*

- It is difficult to be treated from TB, as the immune system is destroyed by HIV, the immune system does not work, if you have AIDS, the more likely a man can die ...

- If a person has HIV, it is more likely that this person will be infected by TB, than people who do not have HIV, because his body is weakened...

- When a person's immune system is weak, it will be easier for the disease, tonsillitis and bronchitis and tuberculosis are all quickly introduced into the body and begin to develop in parallel ...  
- The body cannot fight. There is a favorable environment for the sticks (tubercle bacillus), and it begins to develop ...  
- The HIV-infected man dies, he dies of any disease, because that is associated with many diseases like TB, hepatitis, diabetes, etc. ...

Below is a quote, which in general indicates at the understanding by respondents of the adherence to ARV therapeutics.

- if a person has HIV, TB is not always detected. It can be discovered in 15 years because the HIV-infected person may live another 25 years. And if he takes ARVs, he can live the rest of his life. For this he needs to live a sober and healthy lifestyle ...

As for the questions regarding treatment of TB in PWLH, respondents provided the following information:

-also, it does not matter. Treatment is parallel ...  
-there is the scheme, a person firstly takes anti-TB medicines, because ARV therapy is not always combined with anti-TB medicines, there are more side effects, etc. so a person should be treated from one disease ...  
- In addition to TB medicines, one or two pills are taken, further and constantly have to drink all the life, kotrimazol, in my opinion ...

Respondents are aware that the lack of adherence can result in resistant forms of TB.

-in order not to have stable form (comment: all participants shared this reply) ...  
-to avoid infecting their loved ones, in order to live longer. To quickly recover. In any case it will be treated, so at the first sign to begin treatment. Bacillus "Kochav" adapts to medicines. If a person stopped treatment the first time, the second time the same medicine will not help. There will be need for more powerful drugs. This is called "multi resistance." It is like the cultivation of fruits and vegetables ...  
- is a socially dangerous disease, it is, first, nor only for you, it influences surrounding people, more people die of it than of AIDS and HIV ... (Bishkek)

### 6.2.3 Stigmatization

According to the majority of PWIDs, almost all are equal before the TB infection. Many respondents believe that TB prevails among vulnerable groups of people.

-any person ...  
-vulnerable populations ...  
- yes, but mostly vulnerable people are more likely to be infected with TB, they are drug addicts, convicts, people living with HIV, migrants, SWs and staff of places of detention, because they are in close contact with the prisoners ... (Osh)  
- People who have humidity in their houses ...  
-people who have an unhealthy life style, first of all, and those who communicate, who are not following hygiene measures  
- People who are in prison, they do not have any vitamins in damp places... (Bishkek)

Almost all of the respondents are aware of those who are ill with TB. To the question: "Do you know someone who is sick or ill with TB?" they said - "We know and communicate."  
The attitude of PWIDs to TB patients is, in general, loyal.

- *It is necessary to provide moral support ... and try not to get infected ...*
- *I am ok with it, you just need to follow hygiene when talking to a person who is infected with TB ...*
- *The same people, like everyone else, they just need to be treated and that is all ...*
- *If it is a close person, then of course you want to help and support even just by one word of course*
- *sympathy ... (Bishkek)*
- *They are the same people, and we respected them before and were friends and now continue to be friends and communicate with them. Our attitude has not changed. We will provide any help, support, etc. moral support ...*
- *We slaughtered a dog and brought it to him, because a dog's fat and meat is very nutritious and curative for TB. It was used before. Previously, the doctors recommended, and it is now standard treatment ...*
- *We can buy horse meat or mutton and bring it to him in order he eats well and does not lose weight ...*
- *Moral support is also important. If a person is under pressure about being ill with TB, it will get worse, and if we say that he will recover, it will be easier to fight the disease ...*
- *I think you cannot pay attention to this disease when dealing with patients! This is the support ...*

Some said that they are afraid of being infected.

- *We're afraid ...*
- *We are not afraid, just understand, and try not to approach them, not to talk, in order not to be infected...*
- *Just get scared, and that is all ...*

At the same time almost all PWID would have communicated with people with TB.

- *Yes, we will continue ...*
- *We would have communicated as usual...*
- *We would have talked to them, anyway. For example, it is a loved one, friend, yes, how would you have him away from yourself...*
- *And if the husband or daughter is ill, how will you turn your back to them...*
- *A disease is not a reason to distance yourself from a person .*

According to the majority of PWIDs, people who have risky lifestyles can be infected with tuberculosis.

- *who have a weakened immune system ...*
- *those who have firstly a wrong lifestyle, second, poor nutrition, if you communicate with those people who have tubercle bacilli, they can infect you if your immune system is weakened, in my opinion, there are three reasons ... (Bishkek)*

Reasons, because of which people have TB, are stigma and lack of reliable information.

- *Because there is no information in a society ...*
- *if a person is ill, he is ashamed to talk about it, and is afraid of what people think or say about them, and this makes a disease progress. He lives in the mahalla and thinks that people will discuss his disease or turn away from him, etc. It is stigma ...*
- *He takes medicines and once he feels better he starts thinking, why shall he continue to take medicines ...*
- *it is possible, that at any stage medicines have side effects, and he stops taking medicines ...*

Required support when being treated for TB can be classified as follows:

Financial:

- *financial support is required...*
- *aid...*

Moral:

- *family, friends support ...*

Support of outreach-workers:

- *Outreach-workers should always accompany not only now, but in future, because it is easier with them...*

The need to improve the attitudes of doctors towards them, and getting support in regards to the renewal of documents, were also listed.

### **6.2.4 Motivation for applying for and getting treatment for TB**

The main motivation for getting treatment from TB is preserving the health of close people, particularly, the fear of infecting them.

- *those, with whom we live and communicate with, i.e., friends, relatives. We cannot infect them ...*
- *health of close people...*

The most preferred channels of information are disks, brochures and leaflets. At the same time, there were suggestions for arranging meetings with a specialist, where they can have discussions in questions-answers format.

As for the need for further information, the respondents could not clearly formulate their needs. Overall, they indicated that they have all the necessary information, but are not quite sure of its completeness.

Some pointed out the need for the following information:

- *about new treatment methods, new medicines. Earlier they took three or five pills, and now the number of pills is smaller. And beside this, it would be good to know what medicine made up to treat TB and other diseases ...*
- *statistical data about those, who die of TB in the world, in the Kyrgyz Republic and in the region and in Osh*

The language of information provided on TB depends on the location of the respondents. In Bishkek and Sokuluk the preferred language is Russian, and in Osh the preferred languages are Russian, Kyrgyz and Uzbek.

## **6.3 Migrants**

### **6.3.1 The level of knowledge, practice and behavior related to tuberculosis and TB/HIV**

#### **Tuberculosis**

Migrants demonstrated thorough knowledge about TB. Participants pointed out that the disease is contagious in nature and is transmitted by airborne droplets.

- *TB is a disease that is transmitted by airborne droplets ...*
- *But compared to HIV, it is curable ...*
- *If a person takes timely action and gets treatment, it can be cured ...*
- *It is an infectious disease that is transmitted through saliva, shaking hands, using the same glass and so on ...*
- *There are closed and open forms of TB ...*

- Every person has body sticks, functioning of these sticks lead to tuberculosis ...
- TB usually can be caught in damp places ...
- There are more chances of being infected in stuffy rooms, where there is no fresh air and no sunlight – i.e., can be transmitted through the air, but if you ventilate the room regularly and hygiene can ensure a healthy life ...
- TB - an infectious disease that is spread by sneezing, coughing ...
- A person with tuberculosis coughs for 2 weeks, there is phlegm, high perspiration, and because of a loss of appetite, the patient loses weight ...
- Mainly TB can be obtained in public places through the air ...
- Through food, I heard through the seeds as well ...

The following were named as the main symptoms by migrants: cough, temperature, sweating, loss of weight and appetite.

- endless coughing
- High temperature (37degrees and above) ...
- Sweating, loss of appetite ...
- A lot of sneezing, losing weight, losing appetite ...
- and even gets black or dark color of the face ...

Common transmission ways are through airborne droplets, through sneezing and coughing, utensils, kissing, etc.

- If a person has open forms of TB, even when you sneeze, or cough it can be transmitted ...
- A handshake, a kiss and so on ...
- through the air, dishes ...
- through the air, through sneezing, coughing ...
- Droplet ...

According to the majority of migrants, TB can result in death, disability, or other diseases, if a person does not follow the main conditions for the treatment of TB, in particular, compliance with treatment, hygiene measures.

- If the disease is neglected, a person can die ...
- He may die if not treated in time ...
- A person can rapidly get other diseases, etc., unable to work, can become disabled, will be a carrier of the virus ...
- patient is coughing a lot, thus weakening his lungs ...
- If a person with TB is not treated, will not stick to a diet, take medicines, in the end, he could die, plus he can infect others ...

Most FGD participants found it difficult to answer the question on how much time is needed to treat a disease.

Some respondents though that it takes from 6 months and more.

According to almost all respondents TB is curable, if relevant measures are taken in time.

- If a person has initial light form of TB - it is curable, and if a person has a severe TB form, it will be chronic ...
- if a person is treated for TB within 2 months, it can be cured ...
- a person must have faith, hope, because - if people want to try and get rid of TB, it can be cured ...
- there is a need to follow all the doctor's prescriptions ...
- Treatment of TB does not require money, i.e., at the expenses of the state TB can be cured for free...

The range of replies to the question regarding measures to reduce the spread of TB included wearing masks, hygiene, and other preventive measures. In particular, each person must give due attention to the prevention of TB. Preventive measures should be implemented through regular examination for TB.

- wear masks ...
- hygiene, to have a separate bowl, toiletries and beddings ...
- every year a person needs to be tested (X-ray) and examined not only himself, but the whole family ...
- during treatment TB patients should be under the constant supervision of a doctor ...
- First of all hygiene, nutrition, improve immunity ...
- To be tested in time ...
- It is necessary to examine yourself at least once a year ...
- Monitor own health ...

Most migrant respondents were examined for TB within last 12 months, when being employed, during pregnancy, etc. There were such respondents, who did not rest within the last 5 years, as they lacked time.

All respondents, who took examination, said that they had received the results.

- a person gets results when result is negative, and if the results of testing are positive, then a person should go to a TB specialist ...

### **Applying to medical institute**

Almost all migrant respondents indicated that if a person has TB symptoms, he must see a doctor.

- He has to complain about not feeling well, and contact a doctor ...
- As soon as he has symptoms of tuberculosis such as sweating, weakness, fever, he should immediately consult a doctor. As he is likely to infect people around ...
- Of course first of all a person needs to see a doctor ...
- to the doctors ...
- TB specialist ...
- to a clinic near the place of residence ...
- TB clinic ...
- hospital, a person should be referred to appropriate authorities, and then to take the necessary tests ...

Some respondents indicated the use of a X-ray to identify the reasons of illness.

- X-ray...
- X-ray first and then a doctor...

### **6.3.2 Obstacles in applying to medical institutions and getting treatment for tuberculosis**

Different common circumstances and the lack of money were named by migrants as the main factors, which impede applying for aid and getting treatment for TB.

- Mostly family circumstances ...
- Lack of time, all kinds of family problems ...
- Lack of money...

Almost all respondents in this category did not see any barriers in **self-applying** to medical institutions.

When detecting TB symptoms, possible stigma, mental trait, and financial difficulties can be considered as barriers.

- Attitude in relation to TB patients ...
- we are Kyrgyz, and we usually suffer from illness for a long time, and then, when our health is in a critical condition, we go to the doctor ...

*-lack of money (financial support). For example, when you are sick, you want to take taxi, in order not to worry and not to be of a danger to society ...*

According to the majority of migrants, when applying for aid, attitudes of doctors--both to patients and towards their professional duties--plays an important role.

- A greater role is played by the doctor as well, now money solves any problem, if you want to be examined properly, you must give money ...*
- It depends on the doctor, if he loves his job, he will work well ...*
- There are still problems with consulting with a doctor ...*
- I think that the doctors are good and help the sick people ...*
- One day my cousin wanted to go to the hospital to get treatment for TB, but he was not accepted and the doctors said that they only accept by place of residence. We used a different approach and finally with the help of our friend he went to the hospital and was registered ...*

### **Awareness about HIV**

All respondents unanimously answered that HIV is a human immunodeficiency virus. Some added about incurability and ways of transmission.

- it is a disease that is not cured ...*
- it is not curable ...*
- I know that there is no vaccine against HIV.*
- it is transmitted only in three ways: through blood, sexual contact and through the mother's milk. It is not transmitted by shaking hands, communication, kissing, through utensils, etc.*

When answering the question about HIV transmission ways, the replies of one or two respondents were enough, as others agreed with their replies.

### **How HIV is transmitted**

- Three ways of transmission: during pregnancy, through sexual contact, blood ...*
- When using shared needles, razors ...*

### **How HIV is not transmitted**

- It is not transmitted through the air, and through a kiss ...*
- It is not transmitted through communication and everyday activities...*
- It is not transmitted by droplets ...*
- Saliva...*

All migrant respondents said that an HIV test is the only way to detect HIV.

The vast majority of respondents do not know about the window period. Answer of only one member indicates at low awareness of the respondents of this issue.

- "window period" - temporary interval between HIV and AIDS...*

According to most respondents, a person, who looks well, can have HIV.

- externally it cannot be detected, it appears in some period of time ...*
- a person can live with HIV for 10-15 years...*

Migrant respondents think that:

- no, a person with HIV, for example, can have legs, vessels pain or can have a high temperature, but unless a person takes a test, it is impossible to diagnose ...*

To the question regarding the frequency of HIV testing, a more or less unanimous answer was not obtained.

- once a year ...*
- Twice a year ...*

- *Every six months ...*
- *One or two times a year ...*
- *1 time in 3 months ...*
- *1 time in 6 months ...*
- *every month ...*

Answers of some respondents about their last HIV test indicate that they do not follow the principle of regularly being tested for HIV. It happens due to some circumstances.

- *A year ago ...*
- *Honestly speaking today is the first time ...*
- *Last year in March ...*
- *A month ago ...*
- *Twenty days ago ...*
- *Last year in October ...*
- *Four years ago ...*
- *a month ago ...*
- *5 years ago, when I was pregnant ...*
- *a week ago ...*
- *six months ago ...*
- *half a year ago ...*

All respondents obtained results of HIV test, except one.

- *I have not obtained it yet, as of only 1 week ago I undertook HIV testing...*
- *next day we already had a positive or negative result ...*
- *my doctor called me and said that the results of tests are ready ...*

Only one participant responded to the question: "What is ARV therapy?". Others believed that this it is a consultation. All other participants of FGD had difficulties in answering. No participant knew about the importance of adhering to ARV therapy.

### **Awareness about AIDS**

As for AIDS, the following replies were received:

- *The last stage of HIV ...*
- *A disease that cannot be cured, with a fatal outcome ...*
- *Acquired immune deficiency syndrome ...*
- *HIV is the initial form, AIDS is a chronic disease ...*
- *HIV - human immune-deficiency virus and AIDS is a severe form of it ...*

Respondents did not have information about HIV/TB co-infection. Only a few respondents answered the question regarding the influence of HIV infection on a possibility of being infected with tuberculosis. But replies were of a general character.

- *Progresses, accelerates disease, such as tuberculosis ...*
- *TB patient is weak, and quickly takes other diseases ...*
- *as a severe form of a disease ... 2-3*
- *weak immune system ...*

Tuberculosis of PLWH is detected through testing, i.e., it does not differ from the general population.

- *Pass the tests ...*
- *See a doctor ...*
- *Pass x-rays ...*
- *through tests, x-rays...*

Treatment for TB in people living with HIV should be done under medical supervision. In particular, the respondents' answers to this question indicate that they do not see any difference between the treatment of people living with HIV and the treatment of others.

- *Always be under the supervision of doctors ...*
- *follow all the recommendations of the doctors ...*

- *To take all medicines in time ...*
- *you have to be under constant medical supervision, and to take prescribed medicines in a timely manner ...*
- *diet, it is necessary for a patient to have good food...*

The respondents' answers about the need for commitment towards TB treatment shows how respondents were not aware of resistant forms of TB. Thus, only one participant from two FGD provided information on this.

- *No one is safe from it, and there will always be the possibility for infection ...*
- *To monitor the health and lifestyle...*
- *"Better safe than sorry" ...*
- *a person must think not only of himself, but also to think about close people ...*

*In order a person does not have severe TB form, which is incurable*

*-it is very important, for example - migrants, they live in groups of 5/10/20 people in a room, people of different levels, and it is not known who has what disease, plus the migrants have poor nutrition, which leads to various diseases, and leads to TB as well ...*

### **6.3.3 Stigmatization**

In particular, according to many workers, those people who have living conditions which contribute to the development and spread of TB are most at-risk for getting TB.

- *People with a weak immune system ...*
- *Everyone, no one is safe from this ...*
- *prisoners ...*
- *The people who live in damp ...*
- *people who are / were in prisons ...*
- *people who are engaged in housekeeping, animal breeding ...*
- *those who have a weak immune system, and poor nutrition ...*
- *drug addicts ...*
- *those who do not follow hygiene ...*
- *Migrants ...*

Epidemics of TB occur because of the following reasons:

- *A weak immune system, poor nutrition ...*
- *when people are not examined in time ...*
- *Neglect own health ...*
- *do not follow personal hygiene, health ...*
- *because of the weakness of the immune system, because of bad nutrition ...*
- *because of the dampness, lack of sunlight, solar heat ...*
- *because of the poor conditions of life ...*
- *Because there is no information in the society ...*

People with TB invoke sympathy among migrants.

- *Sympathy ...*
- *Sorry ...*
- *Desire to help ...*
- *Because they also have the desire to live, to communicate with others...*
- *I think that they are ordinary people, if they are treated from TB in time, they will be the same as we are...*
- *he was an ordinary man, but he should recover in time for yourself, for others ...*

Some migrant respondents have friends and/or relatives with TB.

Some participants have friends who died of this disease.

- I have a nephew ...*
- I also have a child - a nephew, he was infected by his friend, whose mother was ill with TB, but now everything is good, he is registered, and every six months he passes the examination ...*
- there are among the relatives, they are tested once a year ...*

Many migrant respondents said that they know and communicate with those who are infected with TB, and they provide them with moral support.

#### **6.3.4 Motivation for applying for and getting treatment for TB**

The main reason that migrants apply for medical services is they are aware of the value of their own health.

- desire to be healthy...*
- desire to have a happy life, and to see life interests ...*

Respondents stated that support plays an important role when being treated for TB. But almost all migrants agreed on the importance of family support.

- All three you mentioned ...*
- It is necessary that a beloved is near and provides support ...*
- Moral and financial support from relatives, friends, etc ...*
- Financial support, because as I said earlier, money plays an important role for seeing a doctor ...*
- Having the money for treatment, a person can apply to private clinics, they will treat much better ...*
- and financial support ...*
- TB treatment is free, and moral support is needed, family support, support of others. For example, if nobody will take away from an ill person and will not communicate with him and help, then all treatment will come to nothing ...*
- moral support is needed in order a person not have depression and for speedy recovery...*
- understanding by others ...*
- any kind of support, but the support of friends, family - it is in the first place ...*

In general, the vast majority of respondents indicated that there is no need for additional information. Only a small part of migrants noted the need, which was not well formed.

- I would like to know more about this disease ...*
- Yes of course it would be nice if all the people, our children knew ...*
- We know only 60-70% of the information about TB, and it would be good...*

Migrants indicated at the desire to get information in Kyrgyz.

- information in Kyrgyz and Russian languages, but more in Kyrgyz ...*

TV channels, printed media, and disks were indicated as the main information distribution sources.

- through commercials, info on TV, radio ...*
- through newspapers and magazines, through brochures ...*
- now almost every family has a DVD-player at home and it would be very good if the information were to be disseminated through CDs / DVDs, not only for us but also for the family and relatives in general ...*
- through trainings...*

- *It is necessary to introduce additional hours into the school curriculum in order that children be aware from school ...*
- *The source of information is poorly developed In rural areas, so I would like to recommend to have field visits groups organized for visiting rural areas ...*

#### **6.4 People living with HIV (PLWH)**

Twenty in-depth interviews were conducted with PLWH. This is conditioned mostly by the necessity to observe confidentiality of the status of PLWH.

In general, the main criterion for the inclusion of PLWH into the assessment process was that the PLWH be infected with TB at the moment of assessment or had suffered from TB last year. This criterion was maintained during the selection of respondents from the group of PLWH.

##### **Main symptoms of TB**

The following symptoms of TB were listed: weakness, high temperature, night hyperhidrosis, cough for more than two weeks, hemoptysis, chest pain, weight loss.

- *weakness, loss of appetite, feeling cold...*
- *cough during more than two weeks, hyperhidrosis, hemoptysis ...*
- *hyperhidrosis, fever, high temperature...*
- *weight loss, bad appetite, skin getting darker, short breath, night hyperhidrosis...*
- *when losing weight and cough with blood...*
- *chest pain, purulent sputum...*
- *chest and shoulder-blade pain...*
- *loss of hair and teeth...*
- *skin getting darker, mainly on the face...*

It is important to point out that PLWH, in particular, described symptoms personally experienced during the TB infection.

##### **6.4.1 Circumstances and reasons for becoming infected with TB**

The majority of PLWH respondents were infected with TB during imprisonment.

They were diagnosed with TB during the regular medical examinations of imprisonment in Kyrgyzstan jails. Respondents themselves listed poor nutrition, usage of shared kitchenware, syringes and being in the cold as main reasons for infection.

- *during the regular medical examination all prisoners had fluorography testing with results showing the possibility of TB infection...*
- *we had poor nutrition there...that's when all of this started ...*
- *we had a sauna there where there was no hot water, only cold water. I was sweating at the sauna and used cold water...I got cold ...*
- *when I was in prison I communicated with people with TB, cooked for them, ate and drank with them. I did not know that you could get infected from them. My TB was progressing also because of the incomplete treatment, I did not take medicine and did not get cured from the primary infection. And here is the result – TB microbes started eating up my body...*
- *first time in a jail. I guess there were a lot of people with TB, probably, I was infected with TB through the kitchenware; we also communicated with each other, and there is shared kitchenware in the kitchenette. Probably these are the reasons. Second time I was infected after the release from the prison and I am currently sick. I got infected last winter... At first I got the flu, then cough and felt cold. I thought it was all because of the flu. Then I started losing weight. I had shoulder-blade pain. I was losing my appetite and did not want to eat...*

- *all prisoners get infected with tuberculosis, they use injected drugs. I, most likely, was infected with both TB and HIV through the use of shared syringes. The person with whom I was put in one prison ward definitely had TB, his last days of life he was laying on a bed, could not move, was dying and I was taking care of him, we drank tea together, probably that's when I got infected with TB. Then I started losing weight, could not eat anything. A medical examination for all the prisoners was conducted and I was diagnosed with TB. I was referred to the medical services where I received the medication. A year later I was diagnosed with HIV. Everyone knows about the situation in prisons – it is a den of TB...*

Some of the PLWH were labor migrants in Russia and these respondents believed that the main reasons for TB infection were related to work conditions. These work conditions included working in the cold and the regular use of alcohol.

- *probably at the construction in Russian. The climate there was wet ...*
- *before that I worked in Russia for two years in very bad and cold conditions. Identification documents were taken by the policemen and I was not able to depart back to Kyrgyzstan. I had to put up with this. When I was sick, I could not find medicine or turn to the medical institution for examination and treatment, I just drank vodka to kill microbes, flu and cough. This life style became a habit. Then I came back to Kyrgyzstan using somebody else's documents. By that time I already had TB, but did not know about it. When I returned my father died and I had a drinking bout. My mom found out about existence of the "Plus Center" ...I got used to this center; in the morning I came to the center without any compulsion. One day I noticed that I have not been drinking for a while! Center's staff offered to go with me for an examination, but I had no money. I received a referral letter and was explained that all procedures are free of charge. We went together and did a test and fluorography. All my problems were identified – TB and HIV. Doctor invited me and showed the fluorography results. There were two large white spots and a few smaller ones in the lower part of my lungs. He (the doctor) suggested for me to get treatment. I could not go back to being normal. But the people from "Plus center" supported me and gave hope. I started treatment right after it...*
- *housing conditions were bad, I had poor nutrition...Before I worked in Russia, from where I returned half alive. Moderator's commentary: respondent is in a very bad state, pale – blue skin color, severe thinness, absence of teeth, incapable of communication, trembling of hands, scars on hands, cracks around the mouth, constant sweating.*

Several respondents mentioned their partner as reason of infection.

- *I suspect that I could have been infected by my husband, who was a drug addict, promiscuous and would not come home for months. Then he got enlarged lymph nodes on his face, neck, hands, lost a lot of weight, coughed a lot, his skin darkened, his mouth bled and he died very painfully. I suspect that my husband had died from HIV and TB complications... I started being ill often: had the flu, cold, cough, and diarrhea. I could not understand what was going on with me, enlarged lymph nodes on my neck and chest enlarged, scars on my hands appeared and I started losing weight...my skin darkened. No explanation was received at the Karasuu hospital except that it is because of stress and nerves... I did HIV testing anonymously, after two days the doctor asked me to retest...I was told that I am HIV-positive. I was not told about the TB infection, although I did the fluorography. It was in 2007 and I had 188 CD cells! Doctors in Uzbekistan were understanding, psychologist talked with me and I realized that*

*my husband died from HIV and infected me as well! I returned to Kyrgyzstan. I came to the Osh AIDS Center where, after a thorough examination, I started receiving the ARV therapy. I lost my job because of my illness, could not pay the apartment rent, was left on the street. I lived with some people I knew, but there was no heating and I was starving, in one word I lived in poverty. I had a high temperature during the week, then specialists from Karasuu office of PAD started searching for me and when they found me and saw my state I was referred to the Karasuu TB clinic. I was examined free of charge. Doctor Aliev observed my state and I was diagnosed with TB...*

Reason of infection – shared syringes.

- *I am a drug addict and that's probably how I was infected. I communicate a lot with other drug addicts, we share syringes, and there are a lot of people with TB among us...*

Almost all PLWH respondents indicated that they consider full recovery from TB possible if a number of conditions are fulfilled, namely – mandatory and continuous use of the assigned medication during the treatment course, along with strict observance of the treatment regime. PLWH also are well aware of the necessity to observe personal hygiene, good nutrition and a healthy life style.

- *of course, it is possible. One just needs to take all the pills that are provided...*
- *it is possible if medication is taken on time, complemented by good nutrition and a healthy life style. The most important thing is to start the treatment. But one cannot get it all at the prison. If you are in such a situation, you need to make everything possible to get a conditional early release...and to start treatment at home under medical supervision...*
- *of course, it is possible to get cured...Tanya helped me a lot. She is a good woman. She also told me to take my medicine...*
- *it is possible, but one needs to do everything that is advised by the doctor: to take all the medicines, eat well, avoid smoking, come to the doctor upon request and do tests and fluorography...*
- *you need to eat well when taking this medicine. You know, for this reason people say "It is easier to prevent, than to treat". It is better to have an examination twice a year, especially now when TB is flourishing in Kyrgyzstan. Too bad I realized it too late...*
- *it is possible to get cured if I will follow all doctors' instructions, avoid drinking alcohol, use the assigned drugs and lead a healthy life style. For this I take pills on time, regularly do tests and eat well ...*
- *it is possible subject to continuous treatment. I will provide my example, I underwent the ARV therapy. I got used to taking the medicine regularly at a specific time, but then I got into the detention center. Although I told and begged guards to bring me the medicine, they refused and my whole ARV therapy went down the drain. I spent 7 days in the detention center and had to start the treatment all over again. After release from the prison I lived on the street and was again infected with TB. For a month I was searching for housing and did not care about good nutrition and medicine...*
- *it is possible to cure if follow everything that the doctors say. Approximately 20 pills need to be taken accompanied by good nutrition, taking of vitamins, immune system needs to be improved...*

#### 6.4.2 Places where PLWH turned to for help

PLWH respondents first of all turned for advice/help to the prison's medical service – PLWH who first had symptoms while being in the prison or TB diagnosis were identified during planned examinations, and then received treatment.

- *at first I turned to doctors in the prison, where I was diagnosed with TB. I started treatment after one week ...*
- *when I got infected in prison I turned to the medical service. Second time, when I was not in prison, I felt the same symptoms of TB, at that point I already was a client of PAD and turned to them. They referred me to the TB clinic for an examination, where I was directed to the TB hospital...*
- *The first time my illness was identified was during the complete medical examination and I started treatment right after it. Before that, during three months I suffered from a cough and pain. Everyone in the prison ward knew about it, but could do nothing to help me. When I was released from the prison one month later I turned to PAD for help and advice...*

But more often PLWH do not seek healthcare early. Many PLWH indicated that at first they waited, practiced self-treatment at home, and only when these methods did not have an effect did they turn for medical advice. The diagnosis would be made using the testing process..

- *symptoms were displayed, but I did not pay attention to not feeling quite well. I turned for help when I started having shortness of breath and a high temperature (Kant)...*
- *I caught a cold, used my own medicine. I was advised to drink oil, but it did not help. I did not feel well and had no appetite, began losing weight and then turned to the hospital (Kant)...*
- *it was approximately one month (period between the beginning of the symptoms and turning to a medical institution). You don't pay attention to some pain, cough, flu, angina (Kant)...*
- *I did not turn to anyone anywhere as I thought that it is all because of poor nutrition. I thought that I did not feel well and was losing weight because we were not fed well in the prison. I did not want to eat because the food was tasteless ...*
- *it was approximately one month (period between the beginning of symptoms and turning to the medical institution). You don't pay attention to it; you have pain but so what? Then when I started getting strong shortness of breath while walking even shortest distance, for example to the toilet at home, and it seemed like I had walked a kilometer, then I turned for help...*

Some PLWH pointed out that when they did not feel well they often got treatment for the flu or cold, and only after the TB was found after TB testing did appropriate treatment begin.

- *everything started with the cold, I thought it was a cold, at first I used medicine to cure bronchi (Kant)...*
- *mother started putting the glass "jars" and I felt better, but you can't do it every day, so mom told me to do tests. I did and got into a hospital...*

Only some people mentioned that when they did not feel well did they go to a medical institution for treatment.

- *first time I turned to the hospital. I was in Russia. I started treatment timely after I received the results of the tests...*

Some respondents indicated that had sought medical assistance for treating TB only after becoming clients of the NGO.

- *I had a cough, high temperature, but did not think I had TB. I continued drinking alcohol and found out that I had TB only after I turned to the “Plus center”. Then I started the treatment. So the first helpers and advisers were specialists of the center. I can’t say anything about the timing as even in the worst nightmare I did see the HIV and TB ...*
- *specialists from PAD came and I turned for help. They took me to the TB hospital. I had a high temperature for one week, but before that I had a cough, high temperature and...after the New Year I was lying in my bed...*
- *I told to my youngest sister, and she already saw my state and called my older sister who is in Russia. They wanted to take me to the hospital, but I said I would go there on my own and ran away. Then employees of PAD found me and took me to their office. Together we went to the Karasuu TB hospital where I did tests and fluorography and the diagnosis was made...*
- *I am PAD client and often come there, participate in the events and the employees of PAD were who I first turned to. It was June 2012. They referred me to the TB clinic...*

### **6.4.3 TB tests and treatment**

PLWH respondents listed standard tests taken before the TB diagnosis was made, in particular, blood and sputum tests and fluorography.

- *I did blood and sputum tests, fluorography, and the tests were the same in prison and when freed...*
- *in prison doctors took the tests. Outside of prison I did tests in the TB clinic upon referral from PAD (when you do tests through them, they are free of charge). In both places I did blood and sputum tests and fluorography...*
- *in several cases respondents pointed out the urine tests along with other tests...*
- *general blood test, urine, sputum tests and fluorography...*
- *fluorography, blood, urine and sputum tests...*

### **TB Treatment**

According to the information from respondents, treatment started almost right after the diagnosis was made. This situation relates to PLWH who received results outside of prison. Those PLWH who were diagnosed in prison received treatment later, for some of them treatment was delayed for several months.

- *outside of prison, after turning to the TB clinic, medication was prescribed and issued. And the schedule of taking medicines was established ...*
- *about TB, I started receiving treatment right after the diagnosis, but I do not know when I got infected...*
- *right after the testing and confirmation of diagnosis. After one day I was put into the hospital because rules are strict in Russia...*
- *I was put into the hospital after one day...*
- *it was faster outside of the prison, I did tests, in 5-6 hours the diagnosis was confirmed and doctors prescribed medication that I took right away. As doctors put it, I was “bombing” my microbes ...*
- *1-2 months- it was in prison. I don’t know why it took so long, maybe because they were processing my transfer to the TB hospital or maybe they just “turned a blind eye”. They know better. We don’t have the right to speak up in prison...*
- *the next day after diagnosis. When test results were ready in the TB hospital. In prison it was one week later because of the preparation of papers. There is no freedom there to get into a hospital any time it is needed...*

- *three months as I was in prison, and it is different there than when you are free...*

According to information from PLWH respondents, treatment was free of charge and was conducted under medical supervision.

- *I received treatment at hospital # 47 when I was in prison. I don't know what type of treatment I was receiving. I just took the pills that were given. Then, when I was released from prison with the support from PAD I started treatment in Osh rayon where I knew my treatment routine well. Kamildjan showed me the test results and explained everything. Together we looked at my fluorography results and he explained to me every "part of my lungs". He made me control my weight...*

Several PLWH had members of their families who helped control the timely taking of medication, but there were only a few such cases.

- *my mother observed that I took the medicine...*
- *my mother strictly controlled because my father also had this disease...*

Some PLWH pointed out that they preferred to receive outpatient treatment as hospitals did not provide convenient conditions.

- *I received outpatient treatment in prison, meaning that I came to the medical service where was provided with medicine and then went back because I was able to move independently and made myself walk. Why didn't I stay at the hospital? I could have if I wanted, but you know it "smells like death there, when you enter the barrack where TB patients are kept. And I thought it is better not to stay there, better for me to walk there and return back to prison ward". 2-3 persons died there every day. Now, here at home, I also get outpatient treatment because of poor conditions at the hospital ...*

Sometimes the selection of outpatient treatment was related to cost reduction.

- *they observe me. I get outpatient treatment. Even though all the medicine at the AIDS center and TB clinics are free of charge, there will be anyways be some expenses that my family or I are not able to cover...*
- *I was treated at the prison hospital. All the medicine was provided by the hospital. I was treated in Karasuu, medicine was also was provided for free. Then after two months spent at the hospital I was transferred to outpatient treatment when I was no longer a threat to society. I started taking medicine at home, and if before I took 15-17 pills every day, now I take them every other day...*
- *it was better in Russia, where I received good treatment at the hospital, medicine was provided in a timely manner, I took more than 15 pills a day, although I cannot recall the names of the pills as there were too many of them. What I remember was ethol, rimphopicin, isoniasid and others...*
- *I spent 10 days at the TB hospital, now I am on outpatient treatment, I take medicine at home ...*
- *The first time I took medicine at the medical service, and now I take medicine at the Hospice where I live and receive treatment. I did not want to go to the TB hospital as I did not have money and no one would visit me there and I had other diseases in addition to TB. I don't buy medicine; I get support from organizations such as PAD. But in spite of the help, there is not enough*

*medicine. I compared and think I received better treatment in prison! It was all for free in prison and here you need to spend money which I don't have ...*

- *I was treated using the “Dos” method at the hospital for two months. This method is when the doctor talks with a patient as if he was a relative, and during the conversation the doctor gives the medicine. I did not notice how I was taking 17-18 tablets during the conversation. Then the nurses did this, then patients repeated one after another and no one threw away the medicine and did not forget to take them on time ...*

Those respondents who were hospitalized indicated that inpatient treatment took about 2-3 months.

- *I was in the prison hospital for two months. Conditions were a little bit better than at the prison itself, food was different but not so much. We received dairy products and sometimes butter. But you will agree with me that this is not enough. Patients like us need to have good nutrition and constantly eat meat and everything nutritious. But where will you get it in prison. So we ate what was given. We did not have a choice. When I was in a hospital in Karasuu, the nutrition and treatment were completely different. Food was provided by out relatives or relatives of those who were in the same ward, and they brought dog's meat which is the main enemy of TB...*

Rarely hospitalization took up to six months, but when it did occur it was probably due to the patient's preference for receiving treatment at the hospital rather than a prison ward.

- *I spent 6 months at the prison's hospital. I just needed to do what they asked me to do and it is better to be in hospital than a prison ward. It is warm, there is no moisture, it is clean and the food is better. I did not get inpatient treatment when released from prison. I receive outpatient treatment ...*

In general PLWH assessed conditions of treatment as satisfactory, but some respondents indicated the limitations in hospitals. Most often respondents from southern region felt this way.

- *I was at the hospital in RF for four months. Conditions and treatment were excellent. In Kyrgyzstan I spent three months at the hospital, but it was terrible! There is a lack of medicine and there is a lack of discipline among patients, their visitors and medical staff. Go - around is not held based on a schedule. All these limitations need to be eliminated because instead of being cured, the patient gets depression because of the situation at the hospital ...*
- *after ten days of hospitalization I wrote a refusal and went home. I liked nothing at the hospital. Unless hygiene/sanitary conditions improve and the attitude of the junior medical staff change for the better, and the patients' discipline develops then one can receive treatment there and kill TB forever ...*
- *two months sharp. I was satisfied with everything! Starting with the relations with doctors and medical staff and finishing with the treatment. Because in comparison with the Osh TB hospital in Karasuu, this was much better. I learned from other patients in PAD where there are people like me and they all tell it. That is why I can tell for sure that we were treated well in Karasuu. Food was good as well. But most importantly, the attitude of doctors was great. My doctor treated me in a motherly manner...*

PLWH from Kant city almost altogether pointed out thorough attention of the medical personnel towards the necessity for completing treatment until the end in order to get cured from TB. Usually this was done through conversations.

- *we talked. If you take pills you can suppress the disease. Tuberculosis can be cured. If you take pills and do everything on time it can be cured. If you don't take pills then you will not be able to fight the disease...*

Only some respondents characterized doctors' attitudes as formal.

- *doctors told me that I need to complete the treatment as it is better for me; this is their job, they have to say this and they did...*
- *when I was at the TB hospital located on Petrovka street, doctors did not really insist. They said "here is your medicine, take it, here is your shot, get it". There was an indifference from their side...who are we for them- nobody, simply criminals with the diagnoses. When I was outside of the prison I received treatment with a different approach. I was supported, calmed, received advice, doctors were interested if I took the medicine, and were interested in how I felt after and stuff like this...*

In general, PLWH respondents pointed out the thorough attention of medical personnel on the issue of the necessity for completing treatment.

- *doctors are doctors in prison or outside of it. They insist on the completion of treatment. But it was stricter in prison. I was afraid to go back to the prison ward and did everything the doctors told me to do. You can even quit treatment outside of the prison. You have to force yourself to continue and this is what I do. In addition Kamildjan ake treats me like his "brother" and after talking to him I could not let myself quit the treatment...*
- *in Russia, yes doctors insisted on completion of treatment so that there are no centers of disease. But when I was at our hospital, medical personnel tried to "get rid" of me as soon as possible. They said it was dangerous to stay there as my organism was weak and I could get infected with an open form of TB ...*
- *when I refused inpatient treatment, the doctor did not let me leave, they insisted on completing the treatment, but I explained that I felt worse from all the mess in the hospital. I took the responsibility and wrote a refusal from the treatment ...*
- *of course, but it was not compulsory, but the "Dos" method was used. During every examination, doctors told us about the importance of completing treatment. They shared with us bad stories about patients who decided to terminate the treatment. Doctors explained the results of completing of treatment, what will change in our organism and behavior, that we will care about our health, will gain weight and our appetite will improve...*

#### **6.4.4 Information about TB**

PLWH respondents also pointed out that they were satisfied with information received from doctors. A lot of respondents, in addition to conversations with medical personnel, indicated free access to printing materials at the medical institutions and NGOs.

The content of discussions and printed informational materials included the importance of completing treatment and the need for uninterrupted treatment.

- *Everywhere, everyone said "take medicine if you want to get cured"...*
- *I am satisfied because doctors in the AIDS Center and TB dispenser provided me with brochures. I also received moral and financial support from PAD. I also*

- received brochures at the PAD. But most important was the referral letter that helped me go through an examination free of charge...*
- *I learned how important treatment is and received different advice. Mainly it all depends on yourself; if you want to live then you will take the treatment seriously. And, of course, support from the medical staff is necessary. I wish there were more centers like PAD. They provide good support. Thanks to them...*
  - *I received information only when released from prison. I mean brochures that were provided by Tanya. I read some information and learned useful information from the placards placed at the TB hospitals. I am glad...*
  - *at the prison hospital I did not know a lot of information; I heard something from other prisoners who had HIV and TB. When I went through treatment in the Osh area doctors explained everything in detail. They told me that treatment should last a long time and should not be interrupted. Doctor Kamildjan himself prescribed me medication and explained how many pills should be taken. He presented me small books with information about TB. I read it all...*
  - *I am satisfied. Due to my long-lasting illness I received so much information that will be enough for my future generations. I received information in all institutions where I went. I also participated in a seminar on TB organized by PAD...*
  - *The first information I received at “Plus center” before I was diagnosed with TB. When I talked with the doctor I received a lot of brochures from them, who also explained me about the consequences of having TB. There was also a lot of information available at the hospital which was placed on information boards. I am satisfied with the support provided by the staff of the “Plus center” as well as support provided by the doctor at the hospital, but I am not satisfied with the medical personnel...*
  - *there is enough information. In prison I saw how people became corpses. Outside of prison information is everywhere. You constantly receive brochures at PAD, talk to people, there is enough information in all medical institutions and Hospices. I am grateful to the medical personnel...*
  - *mainly we received booklets, but conversations with doctors and their support produced a greater effect. Sometimes my doctor would bring food and fruits from home. I am grateful to the doctors and also to the staff of PAD of Karasuu. They were the first to provide me with help ...*

Almost all respondents know about the importance of completing treatment. These conditions are necessary to prevent the development of drug resistance that results in a decrease of efficiency of treatment. Not completing treatment also leads to the development of the multi-resistant form of TB. All this information was received by PLWH during conversations with the doctor, from printed materials, through participation in trainings and consultations with NGO staff.

- *as explained by doctors of the TB clinic of the Osh area, the TB treatment course lasts from two to nine months. Treatment needs to continue until all TB microbes are killed. There is a lot of medicine that needs to be taken simultaneously, in accordance with the schedule, but under strict supervision of the doctor, because the doctor decreases dosage gradually by controlling TB patient’s state ...*
- *as I understood, the treatment needs to be complete. For example, I started but did not finish it. That is why I think that because of the lack of persistence I still did not fight TB fully ...*

- *in order not to die, especially because I am HIV-positive. I have kids who I don't want to become orphans. All of this was told by staff of the "Plus center" that referred me to PAD as well as by the doctors of TB clinic and hospital ...*
- *in an organism, tubercle bacillus mutate. When I quit taking the medicine, these bacillus are not destroyed and instead adapt to the medicine and the medicine no longer is effective...*
- *if I interrupt the treatment, my organism will begin fighting with the medicine that I take. In other words, medicine will become useless and the disease can escalate. Taking ARV medicine cannot be interrupted even for a day, because the immune system weakens...*
- *after I felt the "effects from discontinuing taking TB medicine" I learned how important it is not to interrupt treatment. When you stop taking the medicine, microbes reappear. This is what happened to me. I stopped taking anti TB medicine and "microbes again were inside my organism". ARV medicine needs to be taken constantly to support the immune system. If the immune system is weak, the organism's resistance to even the weakest diseases disappears...*
- *when you don't take pills, TB can repeat and can "reopen". When it "reopens" you can infect others. Your mother, your father. Then you will end up in a hospital. It is bad there...*
- *if TB treatment is interrupted it can transfer into an open form and will become fatal. I can die, where from one side HIV devours me and TB will do it from the other side. That is why it is important to continue TB treatment. Now, when TB aggression has decreased I was connected to the ARV therapy. At first I did not feel well, but then all became normal. Now I take medicine in accordance with schedule ...*
- *I know if TB treatment is interrupted, bacillus in lungs develop immunity to the TB medicine and next time the medicine will have no effect. My doctor explained this. If treatment is uninterrupted and accompanied by good nutrition, TB is killed forever...*

### **Completion of the treatment**

There was no single conclusion on this issue as some PLWH respondents try not to interrupt treatment, whereas others discontinued treatment due to different reasons, which including side effects, bad nutrition, travels, etc.

- *yes I missed taking pills and did not take all of them, because there were so many of them and they are so strong and I was told that when one takes them the nutrition should be good. I had poor nutrition, ate soup with cabbage and water with a little bit of oil inside. I was told that in the case of bad nutrition, the pills will "eat" me and I will get problems with my stomach...*
- *sometimes happened that I forgot to take medicine and then I would get a cough, weakness and shortness of breath ...*
- *sometimes I travelled somewhere and had to stay away for 2-3 days, that's when I discontinued taking medicine ...*
- *yes, sometimes I did not take TB medicine because there were so many of them. I felt sick of them, so I stopped taking pills for day or two, not more. ARV medicine I took constantly, at 8 am. And 8 pm. and before I went to sleep at 10 pm. ...*
- *when I was in prison I would miss taking medicine, because we did not have good nutrition. When I was released I would miss it sometimes because of the conditions of life. Now at Hospice I do not interrupt my treatment, I control myself ...*

Many PLWH did not interrupt treatment because of their personal beliefs and due to the external support.

- *no! Medical personnel at the hospital observed the continuation of treatment using the “Dos” method, then I began controlling myself, especially because I am on ARV therapy as well, that does not allow for interruption...*
- *no I did not interrupt treatment. I was supported by my relatives – mother, father and my spouse. They always controlled me taking the medicine. I received medicine at the TB clinic. I have control all over me...*
- *no! At the hospital, a doctor would always control, at home I controlled myself and my mother and spouse observed it...*

#### **6.4.5 Stigma and discrimination**

A lot of PLWH respondents do not disclose their TB status to other people due to the fear of being stigmatized.

- *it is better if no one knows. No one knew about it all these 11-12 years. So better if they do not know...I don't want it, I am afraid of it...*
- *I try not to tell friends and people I know in order to avoid stigma ...*
- *no I did not reveal it, how can you tell people that you have a tuberculosis. People will turn away...*

Respondents can disclose their disease to close people including mothers and/or spouses because only they can provide financial and moral support.

- *my mother, my ex-spouse. They knew that I am under treatment. My family supported me. They sent me pouches with sugar, nuts, something nutritious. Now when I am close to them I feel calmer...*
- *only my brothers knew, they had sympathy for me...they will understand, will not panic. My mother will also understand as I am her child, but I cannot tell her about it, as she has already worried a lot because of me ...*
- *all my relatives know that I have TB. No one knows about HIV as it is unacceptable for Muslims. This is very frightening ...*
- *only my work colleagues knew that I was at the hospital in Russia. I did not tell anything to my parents. When I returned to Kyrgyzstan my relatives learned about it. My mother took me to the doctors and visited me at the hospital. You can't hide the truth...*
- *at first I told my mother and my spouse about my tuberculosis infection, but only my spouse knew about my HIV infection, but she does not have HIV. The reaction was shocked. But I told her that TB can be cured if I don't interrupt the treatment. My mother said that it is Allah's will! This is my punishment for heavy drinking. She told me to “open my eyes” and God will give me another chance! They started supporting me, visited me at the hospital every day, three times a day. When I received inpatient treatment, my relatives took care of me and controlled my nutrition ...*
- *almost all my relatives and friends know about it. Yuldash aka knows (specialist from PAD). Relatives worried about me, suggested going to the hospital and getting treatment. Yuldash aka helped me with directing to the hospital. He still is interested in my treatment and asks if he can help me with anything ...*
- *after the second infection, I came to my mother, although she did not want to let me in at first. But after I starting living in the Hospice under the constant supervision of Yuldash aka, I started communicating with my mom. I once came*

*to her and talked about everything I went through. She was calm and the fact that she is a doctor helped; she supported me as a mother and a doctor and said that I can return to a normal life if I do what the doctors say ...*

- *only my daughter knows that I have TB and HIV. Others NO! This is unacceptable for us as Uzbeks. My daughter understands everything, supported and still supports me, but she probably is hurt because her family was destroyed because of me ...*
- *only my mother and spouse know. What was their reaction? They cried, my wife wanted to leave me, then I explained that I will not die, will get treatment. I gave them the telephone number of Yuldosh aka so they could call him and learn more. They did not call, but believed me. I will receive treatment for my kids...*

#### **6.4.6 Social support**

Almost all respondents mentioned great moral and material support from the NGO.

A lot of respondents shared that they do not experience problems with people because of their TB status as they had told only close relatives and people they trust about their infection.

- *no, I did not have problems, maybe because I had the closed form of tuberculosis and I did not represent a threat to society. Currently I don't know. I don't have such problems. Maybe someone discusses me behind my back, but no one tells anything to me personally. PAD helped me a lot. When I came to them with my problems they did not look at with disdain, but instead calmed me down, said good, kind words, referred to the free of charge medical examination at the TB dispenser in the Osh area. Thanks to them...*
- *no, I did not have problems in the family, on the contrary, my brothers supported me...*
- *no, only mom dressed down me because I was not careful and got infected. But she is the mother and I think she did it only because she worries about me ...*
- *no problems, my mom supports me in everything. I also receive support from PAD, attended the seminar Yuldash aka sent me to, I receive packages with products, have disability status ...*
- *generally I don't have problems and never had! I did not work because I was afraid of my colleagues' disapproval, therefore, I took private orders. Relatives supported me in everything, the staff from "Plus center", PAD called me regularly, invited to the meetings, I received packages with food from PAD and was referred for medical examinations...*
- *my whole life is a problem! I have no family and home! I don't communicate with people other than the employees of PAD, who are understanding and support me at any time. If I do not have bread or food I turn to Yuldosh aka and he tries to get food packages for me. In one word – PAD are my allies!...*
- *I do not tell anyone about my diseases as I am afraid of disapproval. If I die one day, no one will come to my funerals except for my daughter. I do not communicate with brothers and I don't have parents. My husband's relatives turned away and consider me as homeless...*
- *no, I don't communicate with anyone and I don't have a work. Only sometimes I receive products and money from PAD. Relatives help with clothing ...*
- *no, I have not had problems yet and will not have any in the future because here at PAD I received good support. Yuldosh aka every other day asks about my health, advises to start treatment as soon as possible and complete it. If they need a car, they call me and I help, they pay for the gasoline. Apart of them, I do not ask for help from anyone else...*

- *There is an NGO “Antistigma”. They distribute packages, and if they have something for us, they always call and ask us to come. Of course, nothing is free. Mainly they invite me for an interview. Red Crescent packages are given without anything in return. The NGO sector provides support. If there is information they disseminate it...*

### **Expenses for treatment**

A lot of respondents pointed out that are treated from tuberculosis for free. Main expenses they have are for transportation to reach medical institution.

- *yes, I had enough of money because my treatment was free of charge ...*
- *my treatment was free of charge. In addition, they treated me very well. You will agree that there are things that money can't buy. For example, good words in the right moment, even a simple touch of the shoulder says that you are treated as an equal and not disdained ...*
- *my treatment was free of charge. I only spend approximately 50-100 som for transportation ...*
- *I have no money! My whole treatment is paid for by PAD and Hospice. Yuldosh aka provides me with money for transportation.*
- *tests and fluorography were for free, but I spent 10,000 som. I did not know back then what the money was taken for. Money did not matter, my health did matter. I spent around 100 som for transportation each time. Currently I am on outpatient treatment, that is why regularly visit the hospital to get information about changes in my organism ...*
- *no, I don't have enough money because there are always some expenses that are directly related to me having HIV and TB ...*
- *I receive free of charge treatment from the AIDS Center and TB dispenser. I need money for food. As I said there are expenses that are directly related to my HIV and TB status. I take “strong” medicines and for the organism to digest them I need good nutrition. I think we need an organization to support patients like us, the state helps but we need more support. For example, support by additional provisions of food, medicine on a monthly basis. We need society to accept us...*
- *I spend money for taxis. We don't have public transportation in Karasuu (marshrutkas) only taxis...*
- *I don't spend money for treatment because it is free of charge for me. I have friends who have cars and they do not object to driving me to the Osh region when I need it. I don't visit Kamildjan every day...*
- *I don't remember how much I spent in Russia as my colleagues gave my salary to doctors, maybe our foreman provided additional money. Here in Osh I also don't know about the spending because it is controlled by my mother...*
- *it is difficult to answer this question, because all expenses were covered by my mother, she told some things, but hid some things as well. I watched on TV that TB treatment is free of charge because of the funds allocated by foreigners. This trouble came to our home with me and we tried not to tell anyone about it and my mom herself found money for first months of treatment, then it became easier for me as I started taking some private orders and earning some money. I gave all my earnings to my mother, this is how I live and get treatment...*

For PLWH respondents, regular visits to medical institutions for services are not an issue.

- *it takes approximately thirty minutes. The TB clinic is located in the Osh area and there are a lot of marshrutkas (taxis) going in that direction...*

- *it depends. Sometimes it takes thirty minutes, sometime an hour when I have to walk because I have no money. It would be great to receive transportation tickets from the government. We used to have it before.*
- *it does not take too much time because we have no problems with transportation in Karasuu...we have taxis that will take you anywhere needed and it costs 30 som, which is not much and I don't visit my doctors often ...*
- *Kamildjan works in the Osh area and I spend about thirty minutes or hour. Friends drove me there so I had no problems...*
- *I did not have to spend money on transportation because I have a ticket I received due to my official disability status. I have a III group disability...*
- *it takes about one hour to get to the "Plus center", PAD, TB clinic and TB hospital from my home and costs approximately 50 som, which is not a problem for me ...*
- *30-40 minutes. If I need to go to the medical institution or PAD office a car is sent. There are employees of the PAD who have their own cars, but it would be great to receive transportation tickets...*

### **Family support**

Almost all PLWH respondents who had families pointed out that they receive moral support, sympathy and care.

- *yes, my family members worried, especially my mom. When I was in prison, she tried to send me pouches more often with butter. Now, I am close to her and she sees what is going on with me, how I go through the treatment. When I am near she feels better ...*
- *of course, my brothers worried about me. They supported me with money for good food and for me not to walk too much and fatigue my organism. They went to doctors with me, talked to them and supported me as they could...*
- *of course, my parents and wife provided support, especially when I was in prison. Now, when I am receiving treatment at home they don't worry. They see how I go to the TB dispenser, AIDS Center, take medicine...*
- *I was rather supported than worried about or they did not want to show that they were concerned. I also try to lessen their worries by regularly taking medicine and visiting doctors...*
- *of course, they worry! They are afraid that I will have a booze and quit treatment. But I show them how I take medicine and inform them when I go to the examinations. This lessens their worries and concerns. For the family it is also important for them to communicate with other people who went through it and learn about their feelings as well...*
- *my mom is old, she worries, of course, but I cannot lessen her pain, I owe her a lot, but can do nothing...*
- *except for daughter, no one worries as I have no one else. I cannot lessen her pain (respondent started crying and could not talk, but said that it becomes better when she cries as she cannot do it in front of daughter)...*
- *they worry, but currently I am collecting all the documents, referral letters and getting ready for treatment. Relatives see it and probably it calms them down. In order not to infect my children, wife and parents, I sleep and eat separately...*

### **6.4.7 Barriers in TB treatment**

In the majority of cases, PLWH respondents indicated the absence of any barriers in TB treatment related to the presence of HIV. A lot of respondents were well informed about the

principle of non-disclosure of diagnosis by medical personnel, so they did not have any fears about this.

- *the fact that repetitive TB infection is the result of the presence of HIV in my organism and that I am HIV-positive is known only by PAD, AIDS Center personnel and you – interviewer...*
- *at first I was diagnosed with HIV, then with TB. Because of HIV my immune system weakened, my organism's resistance decreased and TB bacillus progressed. But my HIV status did not affect access to the TB treatment because anywhere I went for medical help, my data remained anonymous ...*
- *yes, it influences. If I did not get infected with HIV in 2000, I would probably not get TB in 2001 and would not have had second TB infection later. I just don't have resistance in my organism. Only doctors and PAD personnel know about my HIV status, but they are responsible for anonymity. You also told me that all the information revealed during this conversation will remain confidential and no one will know about it, that is why I am talking to you ...*
- *everyone in prison and outside of it knows about my diseases, I don't hide it. When Yuldosh aka gives a referral to a medical institution I go there with him or other personnel ...*
- *I did not suspect I had HIV and TB and it was identified all together. At first I was diagnosed with TB and then with HIV treatment. I cannot tell for sure if I was infected with HIV or TB first. I don't refuse treatment, but I am afraid that my mother will find out that I have HIV! My wife will definitely not tell. For now I and my wife don't have sexual intercourse t, only after I get cured from TB. HIV is not transmitted if condom is used...*
- *yes, probably. If I did not use injection drugs I would not have these diseases. But how to hide it? I have enlarged lymph nodes. Everyone in PAD, Hospice and AIDS Center knows about my status ...*
- *no, before I got TB I knew that I had HIV and was registered at the AIDS Center. When I was referred to the Karasuu hospital I first of all told to my doctor about my status. The doctor understood me...*

Several respondents refused to answer questions related to their HIV status. Such cases were in both southern and northern regions.

- *I don't want to answer this question!*
- *I don't want to discuss my HIV status...*

Some PLWH respondents mentioned that they feel a biased attitude from medical personnel.

- *I think that there is still stigma at the medical institutions. When a person has TB it is perceived as more or less normal, but if there is HIV the doctors' attitudes are different. However, I think doctors should know a lot about HIV as they undergo trainings and should know that person is, in general, not infectious, if they are not practicing unsafe sex. But there is still this attitude in medical institutions...*

In general, almost all respondents pointed out satisfaction with the level of treatment and care. The main argument is the improvement of health.

- *yes, I am until the end of my life grateful to doctors and PAD staff because they are ready to share information and help any time...*
- *yes, I am satisfied. If TB was not found at the hospital, I would not be aware of it, but now that I know that I have TB bacillus in my system I can control the state of my health. TB medicine probably costs a lot, but I receive them for free.*

*If I had to pay for them, where would I find the money for treatment? Anyways, thanks to doctors...*

- *I am fully satisfied because I had good conditions for treatment, including sanitary and doctors at the hospital treated me well. I think that the environment you live in also has an effect on reaching a faster cure. What can be better than to be with your relatives...?*
- *of course, I am satisfied because there is a positive progress in my treatment. Before I took medicine every day, now I take it every other day and fluorography shows that there are changes. Kamildjan aka also told me that treatment has a positive effect...*

It was suggested to enhance nutrition in prisons for TB patients.

- *the most important thing is that there should be good nutrition in prisons because there are a lots of TB patients there and the medicines they take should bring use and not lead to side effects. This is possible only if nutrition is good. In addition, necessary conditions should be created...*

There were also suggestions related to improvement of the material – technical basis of hospitals.

- *the only thing needed is to change situations in our TB hospital, from the entrance to the beds and ceiling ...*
- *absolutely not from level of care and state of the TB hospital, but I am satisfied with the treatment. Everything should be changed in the TB hospital! Rehabilitation should be made, along with cleaning and the establishment of strict discipline for patients and improvement of sanitary/ hygiene state of the hospital...*
- *yes, in our town at this hospital some changes are required. For example, the renewal of beds, the need for variation in food, and trainings conducted for medical personnel so they don't consider TB patients disadvantaged and will treat us as equal to them...*

## **6.5 Conclusions**

### **Commercial sex workers (SWs)**

The level of knowledge on TB in general is full and complete, but some single cases of where there was a distorted understanding of TB transmission ways were observed. Also, knowledge on HIV/TB co-infections, ARV therapy, and commitment to ARV therapy in the northern region is not deep or is absent. SWs from southern region showed a deeper and more complete knowledge.

The majority of SWs responded that there are no factors restricting turning for support or TB treatment. Only some participants from the eastern part of the Chui province mentioned financial difficulties.

SWs in Osh city indicated a number of barriers that can be classified and prioritized as below:

- Financial limitations;
- Acceptance only to specialized hospitals;
- Lack of beds in medical institutions;
- Absence of identification documents;
- Cynicism of doctors;

- Stigma.

The fact that outreach workers provide accompanying services to the medical institutions, decreases imitativeness to apply for health care independently.

SWs' value of their own personal health and health of relatives is a motivation to receive treatment.

SWs have loyal attitudes towards TB patients. There are a lot of TB patients in their environment.

SWs would like to receive information on TB through discussions and CDs in Russian and Kyrgyz languages.

### **People who inject drug (PWID)**

PWID, depending on the region, demonstrated awareness of TB except for single cases where there was distorted understanding about its ways of transmission. For example, some PWID thought that TB can be transmitted "through a handshake". There were also cases where PWID had distorted understanding of TB treatment, where "resistant forms of TB cannot be cured but only suppressed".

A lot of PWID did not see barriers to treatment if they independently sought medical help. Self-treatment occurs in cases where the reason was an absence of identification documents and an absence of accompanying outreach worker who facilitates the process, .

PWID do not stigmatize TB patients.

The main motivation for PWID to seek treatment is the value of own health and the health of relatives, in particular, the fear of infecting relatives.

The preferable channels of information are CDs, brochures and leaflets. There was a suggestion among PWID to organize a question-and-answer session with a specialist.

Language preferences for informational materials on TB depend on the location of respondents. In Bishkek and Sokuluk the Russian language is preferable; in Osh they prefer Russian, Kyrgyz and Uzbek languages.

### **Migrants**

Migrants possess information on TB, HIV, and AIDS, but have almost no information on the window period, HIV/TB co-infection and ARV therapy.

There are no barriers in applying to the medical institutions and receiving TB treatment, but there are some barriers related to the fear of being stigmatized. Also, the individual characteristics of a person have an impact on care-seeking behavior, and result in delays. The main motivation for applying for medical care among migrants is the awareness of the value of their own health.

There is no stigma. Sympathy to TB patients is demonstrated.

The vast majority of migrants indicated that there is no need for receiving additional information. Only a small number of migrants pointed out the need for information, although they did not clearly state what type of information they specifically need. The preferred language for information is Kyrgyz.

### **People living with HIV (PLWH)**

Almost all PLWH stated that becoming completely cured from TB is possible, in particular, if the main conditions related to continuous and uninterrupted use of all the required medication are satisfied.

A lot of PLWH were infected with TB in prisons. During both times when they were in prison and when they were released did they go through blood and sputum tests, as well as fluorography.

In a lot of cases, medication was taken under the supervision of the doctor, depending on in- or out-patient type of treatment.

PLWH indicated free of charge treatment at the medical institution, but pointed out the poor nutrition there.

PLWH indicated a large volume and accessibility of information on TB through medical workers, NGOs and printing materials.

PLWH are well informed about the necessity to complete treatment, which prevents the development of multi-resistant forms of TB. But some respondents interrupted their treatment. PLWH do not reveal the TB status to people except for relatives.

### **6.6 Recommendations**

- There is a need for a wide informational campaign on HIV/TB co- infection, the window period and ARV therapy among SWs and migrants.
- There is a need for dissemination of broader information on multi-resistant forms of TB among all groups.
- The language of information need to be differentiated depending on the group, for example, for migrants the preferred language is Kyrgyz.
- Preferred channels of information in addition to the existing channels are CDs and discussions.