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**Qualitative research among most at risk
populations for TB and HIV in USAID
Dialogue for HIV and TB Project pilot sites in
Tajikistan**

PROGRAM TITLE: USAID Dialogue on HIV and TB Project

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TABLE OF CONTENTS	
ABBREVIATIONS	3
ACKNOWLEDGMENT	4
BACKGROUND	5
1.0. INTRODUCTION	5
2.0. TERMS OF REFERENCE	6
3.0. METHODOLOGY AND SAMPLING	7
3.1. Methodology	7
3.2. Sampling method	8
3.3. Research target groups	9
3.4. Areas covered by the research	9
3.5. Limitations	10
4.0. GENERAL OBSERVATIONS	10
5.0. GENERAL OUTCOMES	11
5.1.1 Analysis of the level of knowledge and awareness of MARPs on HIV and TB	11
5.1.2. Changes in the knowledge of beneficiaries on combined HIV and TB infection	12
5.1.3. Analysis of the level of knowledge and awareness of social and outreach workers	12
5.1.4 Analysis of the level of knowledge and awareness of medical staff on HIV and TB	13
5.2. Change of attitude and behavior on HIV and TB among MARPs groups - PWID, PLWH and SWs.	13
5.3. Analysis of in-depth interviews	20
5.4. Access to health care: obstacles and motivation	21
5.5. Effective dissemination of information and additional information	22
6.0. CONCLUSIONS	22
6.1. Conclusions on knowledge	22
6.2. Conclusions on attitude change	23
6.3. Conclusions on behavior change.	23
7.RECOMMENDATIONS	24
8.0. CONCLUSION	25
9.0.ANNEXES	26

ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
SW	Sex Workers
DOTS	Directly Observed Treatment, Short-course
HIV	Human Immunodeficiency Virus
PWID	People Who Inject Drugs
MSM	Men who have Sex with Men
MoH	Ministry of Health
NGO	Non-government Organization
PHC	Primary Health Care
PLWH	People living with HIV/AIDS
SDC	Swiss Development Agency
TB	Tuberculosis
MARP	Most At-Risk Populations
USAID	United States Agency for International Development
WHO	World Health Organization

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BACKGROUND

The United States Agency for International Development (USAID) has been providing significant resources for the reduction of HIV and TB in the Central Asian region since 1997. There are a number of ongoing projects in the region, which aimed at fighting HIV and TB with the support of the government and international donors, such as USAID and Centers for Disease Control and Prevention (CDC), World Health Organization (WHO) and the Global Fund to fight AIDS, Tuberculosis and Malaria (GFATM). These programs are focused on addressing the issues related to HIV and TB among general population and high risks groups.

The USAID Dialogue on HIV and TB project is implemented by the consortium, led by Population Services International (PSI) and including Project HOPE, AIDS Foundation East-West (AFEW) and the Kazakh Association for People Living with HIV/AIDS, with an objective to reduce the spread of the HIV and TB epidemics among Most at Risk Populations (MARPs), including People Who Inject Drugs (PWID), Sex Workers (SW), Men who have Sex with Men (MSM), prisoners, migrants and People Living with HIV/AIDS (PLWH), in four Central Asian Republics (CAR) - Uzbekistan, Tajikistan, Kazakhstan and Kyrgyzstan.

The qualitative research was conducted in the beginning of the project among PWIDs, SWs, MSM and PLWH in order to evaluate the level of their knowledge, as well as attitude and behaviour with regard to TB, and also to identify the challenges and potential motivation factors for acquiring medical aid and treatment for TB. The outcomes of the research were used as the basis for developing communication strategies on HIV and TB and also for guiding activities aimed at achieving behavioural changes, which lead to the timely visits to medical centers for examination and treatment of TB.

The current research was conducted in order to provide an interim evaluation of the project activities aimed at increasing the knowledge on HIV and TB among MARPs. The results of the research will be used to amend/introduce changes in the project plan to ensure the successful implementation of the project objectives on improvement of the access of MARPs to HIV and TB services.

1.0. INTRODUCTION

In accordance with the statistics of the XIII International Conference on HIV/AIDS (July, 2010), the spread of HIV has increased in the region since 2001, and the number of infected reached 1.5 million people (66% increase).

The majority of HIV-infected people live in Uzbekistan (16,000), Belorussia (13,000) and Kazakhstan (12,000). In accordance with the official data, 4,084 HIV-infected have been registered in Tajikistan between 1991 and January 2012. This number includes 3,144 men and 940 women.

TB/HIV co-infection was registered among 426 persons (as of October 1, 2011), with 190 deaths (source: Health Statistics, AIDS Center, MOH, 2012).

There are several factors contributing to the rapid increase of the number of most-at-risk populations such as PWID, SWs and migrants. These include geographical characteristics of the country, challenging social and economic situation, drug trafficking, poverty and other factors.

Labour migrants are also among the most-at-risk groups for HIV. In accordance with surveys conducted in many countries, regions, which have high rates of seasonal and long-term migration, suffer from higher levels of HIV-infection among general population. Moreover, epidemiological studies of the migrant groups in several countries show that the HIV/AIDS infection rate among non-citizen is disproportionately high.

In addition to the specifics of HIV-infection, the countries of Central Asia also face new problem of the increase of resistant forms of TB (MDR/XDR-TB), which HIV-infected people are vulnerable to.

Tuberculosis is a serious problem for the health of the population worldwide. According to the WHO report for the 2012, "Global Tuberculosis Control", in 2011, there were 8.7 million cases of TB and 1.4 million deaths from it, among those who did not have HIV, and another 430,000 deaths were due to HIV-associated TB. (http://www.who.int/tb/publications/global_report).

Estimated TB incidence rate in Tajikistan is 231 per 100,000, while TB notification rate is 83.6 per 100,000 (Center for Medical Statistics, MoH, 2008). The situation is worsened by the high rates of seasonal labour migration, poor living conditions of migrants in other countries, high level of poverty, poor nutrition, inadequate health services and lack of financial means to access medical services. The overall situation with TB in Tajikistan remains alarming and requires immediate and adequate measures by all stakeholders.

2.0. TERMS OF REFERENCE

In the region with one of the fastest growing HIV/AIDS epidemics in the world, the Dialogue Program Consortium targets MARPs that most likely to contract or transmit HIV and TB: PWID, SWs, migrants, MSM, prisoners, and PLWH. Risk for TB infection is higher among PWID, prisoners and migrants, but is particularly dangerous for PLWH. During the first two years Project HOPE under the Dialogue project specifically targeted PWID and PLWH with interventions focused on TB, HIV/TB, but also covered general TB/HIV co-infection prevention messages and outreach to MSM and SWs.

Mid-term evaluation in the form of qualitative research was designed to be conducted among MARPs to determine the effectiveness of the interventions on increasing group's knowledge, attitudes and practices on HIV and TB, and to improve care seeking behavior and access to

HIV and TB diagnostics and treatment. The result of the qualitative research will be used for revision of the education program for HIV and TB outreach among MARPs.

Objectives

- ✓ To define the level and changes in the knowledge, attitude and practice of MARPs;
- ✓ To define the level of cautiousness, readiness and acquisition of assistance for TB and HIV diagnostics and treatment among MARPs;
- ✓ To identify factors, which prevent access to diagnostic and effective treatment in a timely manner, based on the opinion of the representatives of MARPs and service-providers;
- ✓ To provide analysis, conclusion and recommendations based on the results for future project activities.

3.0. METHODOLOGY AND SAMPLING

3.1. Methodology

Triangulation method was used to insure validity and reliability of findings by analyzing a research question from multiple perspectives.

Two main principles were followed for this research:

- Use of qualitative research methods with some elements of quantitative data;
- Principle of identical methodology used for the baseline survey;

Different methods of qualitative and quantitative data collection were used for the current research, including:

Review of secondary sources.

Research team has reviewed and studied a number of relevant documents and materials (Annex 1). While studying project documents, the main emphasis was made on the goals and objectives of the project, achieved interim outcomes, outcomes of the project monitoring and etc.

The official statistics and data on TB and HIV among most-at-risk groups were also reviewed, including data of independent studies conducted in Tajikistan and abroad.

The results of the project baseline survey has been also reviewed. This review helped to understand the dynamics and changes in the project implementation.

Focus groups

Following the suggested methodology, the focus group discussions (FGD) were conducted among representatives of the MARPs in the areas of project operations based on the existing FGD guideline (Annex 2). Two focus groups were conducted for each of the most-at-risk groups (PLWH, PWID, SWs, migrants). Each group consisted of 8-10 persons.

Information received during focus group discussions helped to identify the cause and effect relationships of changes occurred in the community as a result of the project activities, to understand the attitude of the people to these changes and also to define further actions.

The location of focus groups was acceptable in terms of ensuring confidentiality and also was comfortable for MARPs. For this purpose the offices of NGO were used.

In the beginning of each focus group discussion, permission was received to take notes and confidentiality was guaranteed. In the course of focus group discussions, all questions have been asked and open discussions were facilitated in order to ensure an open exchange of opinions.

Semi-structured Interviews

Semi-structured interviews and questioner (Annex 3) were used among health providers. Questioner helped the team to collect data on the level of knowledge, while semi-structured interviews focused on behavioural changes and workplace practices.

This helped to avoid the influence of the most active providers on the general opinion. The team decided to use individual interviews because it wanted to exclude the situation when the worker responds the way s/he is expected (as medical worker), and not the way s/he really thinks. During the course of the research, this decision was proved to be the right one. Service providers have become a good source of information on the actual level of demand of the project activities as seen by beneficiaries.

In-depth interviews

Ten in-depth interviews were conducted with people living with HIV and current/recovered TB patients based on the agreed questionnaire (Annex 4). Special efforts were made in order to build trust, create comfortable environment and ensure confidentiality. This data helped to analyse those changes, happened with regard to the level of knowledge, behavioural change and possible barriers for accessing health care services.

3.2. Sampling method

The research team fulfilled all the requirements of the client related to the selection of participants/groups for the evaluation. Data collection was conducted in the areas of the project implementation. The research covered beneficiaries of NGOs, which established partnership with Dialogue on HIV and TB Project.

For the selection of health providers the list of training participants provided by project was used to randomly select and invite providers for interview. All selected providers were called up to obtain their consent to the interview, which are mainly conducted in the workplace.

3.3. Research target groups

Groups for the research were formed from the main beneficiaries of the project:

- Most-at-risk populations (PWID, SWs, PLWH, migrants);
- Service providers: outreach and social workers – NGO staff and medical staff of healthcare facilities both PHC and TB.

3.4. Areas covered by the research

The study covered all the Dialogue project sites, to provide data for comparative analysis and a complete picture on the implementation of project activities. All information about the covered sites and the number of participants from different target groups is presented in Table 1 and Table 2.

Table 1 A

District	SW	PWID	PLWH	Migr-s	Outr. workers	ID I	TOTAL
Dushanbe	7	12	23		17	4	63
Vahdat	9	7	7		1	2	26
Qurgontepa	8	11		10	6		35
Kulob	10	13		9	8	4	44
Khujand	10	10			3		23
TOTAL	44	53	30	19	35	10	191

Total number of assessed individuals (by district)

Table 1 B

**Participants of focus group discussions and in-depth interviews
(by gender and age)**

	SW	PWID	PLWH	Migrants
Focus Group	44	53	30	17
Men		48	27	14
Women	44	5	3	3
Average age	38	39	42	36

In-depth interview			10	
Men			9	
Women			1	
Average age			25-35	

3.5. Limitations

There have been no significant limitations in the used methodology. Interview results shall be evaluated with some caution, although it should be noted that all requirements for ensuring reliability data sampling for each group (PWID, SWs) were followed.

4.0. GENERAL OBSERVATIONS

One of the most important observations made during the research is the existing environment based on goodwill and trust. It was obvious that all partners of the project have very positive and caring attitude towards project beneficiaries. Moreover, project beneficiaries expressed their trust towards the staff of NGOs as well as towards social and outreach workers. It was clear from the way the beneficiaries talked about project staff, especially about outreach workers, that they feel safe. These NGOs has become some sort of ‘islands of trust and safety’ for them.

It is possible that trust and respect, which project beneficiaries feel towards social and outreach workers, can be explained by the fact that many of these workers were representatives of most-at-risk populations in the past or they went through suffering due to drug addiction, HIV infection or TB. However, they were able to change their attitude, habits and their life, in general. This high level of trust and respect toward workers is the most important social capital for the successful promotion of the project. The very fact that the head of NGO ANIS has an open house for the individuals from the most-at-risk groups proves their sincere wish to help these vulnerable groups. These types of actions have a very important social meaning, and they should be supported and promoted.

Behavioral specifics of the target groups have been taken into account during data collection. This was ensured with the support from the staff of NGOs and the project. All necessary efforts were made to create trustful environment and ensure that the beneficiaries do not feel any threat to their safety. Some of the SWs had a very low literacy level or could not read/write at all. This created certain difficulties during discussions, and, in particular, when participants were supposed to fill out the tests. However, these issues have been successfully addressed with the help of NGO representatives, outreach workers and facilitators.

It was a very good decision to provide participants of focus groups and interviewees with food packages. Beneficiaries were openly expressing their gratitude to the team.

5.0. GENERAL OUTCOMES

5.1.1 Analysis of the level of knowledge and awareness of MARPs on HIV and TB

One of the main objectives of the project is to increase the level of awareness of MARPs on HIV and TB, including main symptoms, ways of transmission, treatment, prevention, importance of the strict treatment regime, and challenges of stigma and discrimination.

Project HOPE activities in the frame of Dialogue project is focused on TB, and, in particular, on the danger of the combined HIV and TB infection. Although, HIV issues remained as priority ones, the project, in general, paid special attention to the problems of TB infection among vulnerable groups. This focus brings comparative advantage to the project.

Review of the secondary data showed that project's concept to improve the level of awareness was based on the results of the baseline survey. This means that the concept focuses specific actions to address specific needs of target groups. This approach considerably increased the effectiveness of project educational activities, which were conducted systematically and their success is obvious from the project outcomes.

Despite many challenges, adherence to the project goals and objectives resulted in its successful implementation. The Table 2 below provides the data, which shows achieved progress in increasing the level of awareness.

Table 2

**Level of knowledge on TB and HIV
(number of correct responses - in %)**

Groups (n-162)	What is TB?	Ways of TB transmis sion	TB sympto ms (cough)	Can TB be cured?	What is HIV?	Ways of HIV transmi ssion	Can you know about HIV from person' appearance?
PWID (53)	74%	95%	76%	72%	75%	63%	81%
SW (44)	93%	76%	33%	83%	93%	70%	83%
PLWH(30)	82%	86%	97%	86%	86%	80%	79%

Detailed analysis of the data showed that the overall concept and approach used in the project are justifiable. This statement can be proved by the following conclusions:

A) High level of knowledge in the key indicators such as: what is TB; curability of TB; what is HIV; how to find out if there is HIV; can HIV be revealed from person's appearance. In average, the percentage of correct answers 77% to 89% among beneficiaries.

B) High level of knowledge among PWIDs and PLWHA. 75%-76% of respondents answered correctly to almost all questions. This is considered as a high level of knowledge.

However, indicators on the level of knowledge and awareness on HIV and TB among SWs was comparatively lower than in other groups (37%). This fact can be explained based on observations and document review by the following factors:

- Low level of literacy. There were young women, who could not read and write. They could only write their own name. This means that any printed materials are not accessible for them, and regular trainings are not sufficient. Future educational sessions should address this issue.
- This group consisted mostly of individuals, who have just recently got involved in the project. Some SWs, who took part in focus group discussions, have just started their participation in the project, which means that their level of knowledge is not adequate.
- There has been less emphasis on TB among this group during the project implementation as PWID and PLWH have been identified as priority groups for TB interventions within the project.

It would not be appropriate to evaluate the level of knowledge among migrants based on questionnaire due to the very small sampling size. However, the available data shows that they do not have adequate knowledge and awareness on TB and HIV (Annex 6).

5.1.2. Changes in the knowledge of beneficiaries on combined HIV and TB infection

Focus group discussions and in-depth interviews showed that the majority of beneficiaries are aware of the high risk of HIV/TB co-infection. Most of them know that HIV-infected persons are at high risk of getting TB, and know the consequences. They clearly understand why HIV-infected persons need to have regular check-ups and know main symptoms of TB. They also understand the importance of timely and comprehensive treatment of TB infection.

5.1.3. Analysis of the level of knowledge and awareness of social and outreach workers of NGOs involved in the USAID Dialogue on HIV and TB Project

Social and outreach workers are one of the most important sources of reliable information for vulnerable groups. The current research shows that social and outreach workers, who work with PWID and PLWH, have the highest level of knowledge and awareness. Although, only 18 respondents were tested, it should be noted that outreach workers, who deal with PWID, responded correctly to almost all questions and the proportion of correct answers was between 94% and 100%.

This may be explained by the numbers of factors which come up during the interviews:

- Many outreach workers were/are representatives of vulnerable groups, and they understand their problems and specifics;
- They realize that adequate knowledge and awareness are paramount for their health and survival. This is life-saving knowledge;

- Their knowledge and awareness help them to successfully perform their duties;
- Knowledge and awareness were the main factors, which changed their attitude and way of living.

Discussions and tests conducted among outreach workers, who are dealing with SWs, also showed high level of awareness on potential risks of TB infection, way of transmission of TB, window period, danger of TB and HIV co-infection, ARV-therapy, etc. Meanwhile, other outreach workers, for example, those who work with migrants, were less informed about these issues.

5.1.4 Analysis of the level of knowledge and awareness of medical staff on HIV and TB

Analysis of the results of tests and interviews with medical staff at PHC level showed that this group has a general knowledge on TB, ways of transmission, symptoms, TB/HIV co-infection, and etc. However, they could not always respond to some of the key issues, which the project tries to address: stigma and discrimination and window period.

It is also concerning that some did not know the answers to questions on whether TB/HIV co-infection was dangerous or how these patients should be treated.

Tests and interviews among health providers at the primary healthcare level showed that despite having some general knowledge on infections, they do not express any personal interest in interpreting the knowledge they receive or any initiative to acquire additional information.

5.2. Change of attitude and behavior on HIV and TB among MARPs groups - PWID, PLWH and SWs.

One of the most important aspects of the project's sustainability is a change of attitudes and behavior among representatives of risk groups as a result of project activities. Of course, awareness and depth of knowledge is the primary and the most important step towards behavior change. Only possession of knowledge and information will help to change practice and attitude.

Provision of service package on the basis of partner organizations was an important component of the project in addition to systematic educational sessions using 'peer to peer' approach. Such package included counseling and social escort on TB and HIV, assisting in medical examination and treatment, psychosocial and legal counseling, treatment adherence support including food packages. Sometimes, provided assistance went beyond the project frameworks.

«We have assisted our beneficiaries, a married couple, to establish acceptable conditions for living and upbringing their child»

(conversation with the head of NGO)

«When with our support he managed to overcome addiction problem, we helped him to set his private life going. Today, he lives with his family»

(Conversation with NGO representative)

Complex of educational activities and service packages along with activities on capacity building of health care providers yielded some positive results and change in attitudes and behavior among risk groups.

The research revealed the following results:

- **Beneficiaries of the project – representatives of risk groups, changed attitude towards their own health and health of others. They pay more attention to their feelings and sensations; take notice of health problems and issues of concern to others**

«My brother brought me to NGO where I learned about TB. I had a cough for a long time and there, I was examined with the assistance of outreach worker. Thus I was told that I have TB. I was following the treatment principles being well aware that if I don't it maybe be very dangerous. Now I feel good. I never fail taking medicines. I want to cure completely»

(PWID focus-group, Vahdat)

«When I learned about my HIV status and received information from NGO, I became thoughtful about my health. I gave up drinking and smoking. I started tempering and exercising in the mornings. I regularly have medical examinations. I am very concerned for my family and I am very cautious at home. I do not want the accidental cut to infect my children and my wife when they help me. If I have a cold or cough, I go to the doctor and have treatment. I do this not to overlook TB»

(PLWH focus-group, Vahdat)

«I had a medical examination in the 'friendly' office and I received treatment. Sexually transmitted diseases are a big risk for me. That is why I have examination and treatment regularly»

(SW focus-group, Dushanbe)

- **They take measures to preserve their health and health of others. They regularly have examinations and consult about health issues**

«I had an examination because I coughed a lot and I was strongly advised to visit a doctor. I was accompanied by outreach worker to the “friendly” doctor where I was diagnosed with TB and hospitalized. If I had visitors I tried to meet them outside rather than inside the small room. I also tried not to cough and asked my relatives not to visit me very often as it might be dangerous for them».

(PWID focus-group, Dushanbe)

«I am an outreach worker, but if I am asked to go to the hospital where TB patients are held, I refuse. It is dangerous for me, because as HIV positive I am more susceptible to TB. It will be more difficult to cure. I'd better avoid infection»

(PLWH focus-group, Dushanbe)

It is important to note that social accompanying, voucher system of referrals for examinations and creation and use of “friendly” doctors, play a big role in improving of access to the health services among representatives of risk groups.

➤ **Beneficiaries of the project involve people from their milieu in educational sessions and other project activities. They feel socially in-demand again**

«My brother brought me to NGO and I am very grateful for this. I also brought three other people who had similar problems. I have to help them as my brother helped me»

(PWID story, Vahdat)

«There was a young women SW who knew nothing about TB and HIV. I brought her to our office. She started attending our seminars. I noticed that she coughs a lot and suggested she undergoes examination. TB diagnosis was confirmed. She had a treatment. I supported her as much as I could. Now she fully recovered»

(SW story, Khujand)

«I know drug users who work and can afford buying syringe. But I am also aware that when they have health problems they do not know where to go. That is why I visit them and tell them about TB and HIV. I also tell them where and how they can be examined»

(Outreach worker story, Dushanbe)

As we notice, there are some real improvements towards preservation of health and this is due to project's impact. Besides, these results also prove effectiveness of 'peer to peer' approach which is particularly obvious among PWID and PLWH groups. Such approach also useful in SW groups, though its impact is less significant perhaps due to competitiveness of the group members. It has to be noted that in SW groups, care for client is mainly manifested through self-preservation. But such motivation is very progressive on its own and can be considered as a step towards substantial changes in the future.

➤ **Beneficiaries of the project in all groups changed their everyday practices towards less risky behavior**

«I will never share a syringe with others. Sometimes I have to travel a long distance to get the syringe. Now I am trying to have a reserve»

(PWID story, Kulob)

«I always have condoms and I always explain to my clients what it is for. If I am «working» and I know that someone does not have condoms, I call the office or go myself to the office and bring them»

(SW focus-group, Khujand)

«I try to take less clients. I tell them about HIV and always recommend using condoms. I also suggest them to test for HIV. I never provide services without a condom»

(SW story, Dushanbe)

➤ **Beneficiaries of the project have more faith in project staff, social workers and “friendly” doctors working in the project. There is an environment of goodwill, mutual trust and safety. This is a very important achievement for the success of the project**

«Shahlo is like a mother to us. We can approach her with any question. She always listens and helps. She can go to the doctor or to the clinic with you»

(PLWH story about social worker, Vahdat)

«I started treatment and gave it up because I did not believe that I am needed. But here, they treated me very well. They cared about me. They told me that I will cure and that everything will be OK with me. They even bought medicines and other stuff for me on their own money. They were helping me as much as they could. Now my life is much better. I want to pay back by doing the same for someone else»

(PLWH story, Dushanbe)

High level of trust, goodwill and safety are important conceptual elements of working with vulnerable groups of population. Beneficiaries can find answers to almost all questions and problems they have and such answers are provided by partner NGOs. This particular fact helped creating conditions for involvement of all risk groups in project activities as well as achievement and even overachievement of project targets.

➤ **Increased interest of beneficiaries to receive more information about TB, HIV problems and health issues in general**

Information need arose not only from the necessary knowledge of their own health, but also because of the need to inform other members of the group. Being aware and informed means being able to competently and accessibly answer questions asked by others.

«I would like to get more information about TB and HIV. I am interested in new methods of treatment. It will be also interesting to know more about other infections»

(PWID focus-group, Dushanbe)

«If we are trained how to use computer, we would be able to find up-dated information about diseases and ways of treatment»

(Outreach focus-group, Dushanbe)

➤ **Positive life spirit is observed in all groups**

Participants of focus-groups have future plans. They firmly believe that they will be cured of TB. They believe that they can have full value life even with HIV.

«Everything is all right in my life. I want to know if I am able to have another child. I will research and I will have another child. If I have two children they will be happy»

(PLWH story, Dushanbe)

«I fully recovered. I changed. I want to have a second son. I think everything will be all right with me»

(PLWH story, Vahdat)

«I would like to have a profession. For example, I can be a sewer. I could work during the day»

(SW story, Khujand)

➤ **High level of social and civil engagement of social outreach workers and project staff is observed**

It is related to the fact that almost all of them lived through the problems of their beneficiaries. They sincerely understand and sympathize with beneficiaries and that's why the project staff managed to establish trusted relationships.

Focus-group responses and observations showed that partner NGOs are more than only places where vulnerable groups receive help or information. NGOs managed to create an atmosphere of mutual understanding and support. Perhaps this result was not included in the project as an objective, but this is a reality and as we see it, this is the most significant achievement of the program.

5.2.1. Stigma and discrimination

One of the socially meaningful aspects of HIV and TB is the problem of stigma and discrimination of HIV positive or those suffering from TB. Stigma is a serious obstacle for them to seek medical help and its accessibility mainly due to fear of confirmation of the diagnosis. As our studies show, along with economic problems stigma and possible discrimination are the main reasons people prefer not to seek medical assistance. Although many participants did not know the words 'stigma' and 'discrimination', they were able to describe the phenomena and confirm that it takes place. Based on focus-group responses, several types of stigma are identified:

➤ **Social stigma**

*«Before, I always came to this cafe. But when they knew about my status, they told me not to come»
(PLWH story, Dushanbe)*

➤ **Self-stigma** – a type of stigma when a person tries to isolate himself/herself from the society, dramatically limits communications with others, thus also limiting career opportunities. These results in decline of life quality and often loss of motivation and endeavor.

*«I rarely communicate with my relatives. I do not want them to suffer because of me. I am the only person responsible for what happened to me. Often, I do not want to live»
(PLWH story, Vahdat)*

«When he was told that he is HIV positive he was broken down and refused to go home. He wanted to be let alone. And he wanted to take his own life. We had to let him live in NGO for almost two weeks. While there, psychologist was working with him. It was until he realized that he is not alone and life shall continue»

(Social worker story, Vahdat)

➤ **Stigmatization of infected person and his/her children**

«I do not tell my family about my status because I do not want the neighbors to know. They will hate my children and will avoid them»

(PLWH, focus-group, Khujand)

➤ **Stigmatization of the whole family**

«Sometimes people think that this is a family disease. If I do not hide my sickness, they will not treat my family well. They will not invite us to celebrations. No one will marry my daughters»

(SW, TB patient, focus-group, Khujand)

➤ **Stigmatization by close relatives and friends**

«In some families there is no understanding of HIV or TB. They separate kitchen utensils and clothes of infected person. They try not to communicate with him/her or if do, rarely and rudely»

(PWID story, Kulob)

➤ **Stigmatization of girls from the family of infected person** According to beneficiaries, this is a widespread type of stigma. Because of this, girls almost have not chance to marry happily.

«If people know that someone in the family has TB, girl will never be proposed. If this fact is revealed after the marriage, she will be kicked out from the family»

(SW focus-group, Khujand)

➤ **Stigmatization by health workers**

«When you tell them about HIV status, you can see fear in their eyes. They try keeping distance. As soon as you tell them about it, they stop examination»

(PWID focus-group, Dushanbe)

«When I went to a doctor for a blood test, health worker started examination without gloves. I told her about my status and advised her to be cautious. However, she continued working without gloves though it was obvious she was scared. I think they have to have some regulations as to how to deal with us when they treat teeth or for example during surgery. Then probably they will be less scared and more willing to help us»

(PLWH story, Dushanbe)

As a rule, above mentioned is applicable to PHC but sometimes it happens in specialized centers as well.

In most cases beneficiaries of the project prefer apply to doctors working in the project, to 'friendly' offices and specialized centers. With or without social accompanying, they feel more comfortable when served by the trained specialists

Beneficiaries as well as project staff also noted stigmatization by law enforcement personnel, representatives of other state bodies and local administrations. Perhaps, such stigmatization also impacts capabilities and willingness of the state system to provide assistance to high risk groups.

«After natural disaster that happened in our area, many clients incurred damages. I applied to a local administration for assistance. I was told 'they are trash of the society – damp it'»

(NGO worker story)

➤ **Stigma among representatives of risk groups**

«I try to keep distance. I never share dishes. I try to communicate less in order not to get infected»

(SW story, Khujand)

In general, our conversations with risk groups showed that they are friendly towards each other.

An interesting fact was observed during the conversations with beneficiaries: they believe that stigmatization can be diminished if information about ways of transmission, risks or lack of thereof is provided by very credible and trustworthy source.

«After an outreach worker and doctor whom we trust told us about HIV and TB transmission ways, we are not worried any more to communicate with each other because we know that there is no risk to our health»

(SW focus-group, Kulob)

To reduce stigma and its negative consequences it seems important:

- To improve targeted provision of information for beneficiaries;
- Develop strategy on reduction of stigma and discrimination for health workers;
- Improve explanatory work among law enforcement and other state bodies on positive attitude towards beneficiaries.

5.3. Analysis of in-depth interviews

In-depth interviews with HIV positive TB patients were conducted in Kulob, Dushanbe and Vahdat. In total ten people were interviewed – nine men and one woman.

Results of in-depth interviews showed the following (Annex 5):

- Mostly interviewees got TB infection either in the prison or while in migration in Russia, though some of them were not able to answer;
- From the beginning of illness it takes approximately from several days to several months to apply for medical assistance;
- From the moment of application for medical assistance it also takes from several days to a month or longer to be diagnosed. In some cases diagnosis was delayed by health personnel (flu, ARD), and in others – patients themselves were not serious about TB symptoms. It is important to develop measures on improving the diagnostics among this group of people;
- Almost all interviewees began treatment in in-patient clinics with duration from one week to two months. However in majority of cases in-patient treatment was very short. This issues requires consideration at the level of health providers in close cooperation with other stakeholders;
- Majority noted that the basic treatment was free though other financial expenses such as additional medication, testing, transportation, food and others were significant;
- Majority of interviewees continue out-patient treatment. They are monitored by health workers, trained relatives and social workers. However, still, the risk of non-compliance with systematic and regular taking medications is high. Perhaps there is a need to develop additional recommendations for such patients and to more actively involve social and outreach workers. It may also be useful to consider DOTS treatment in partner NGOs;
- Interviewees have good knowledge of symptoms, ways of transmission and prevention;
- They are able to name the most serious TB symptoms (blood spitting, pleurisy, chest pain, high fever) because they had them before they applied for medical assistance;
- Almost all of them stressed importance of following treatment however their medical records shows interruptions of treatment in the past. This demonstrates the need of individual approach to a patient;
- Interviewees have a good idea of sustainable forms of TB and are aware about importance of systematic medication treatment;
- They are well aware of their low immunity because of HIV and this is often a reason for interruption of in-patient treatment in TB clinic;
- They are concerned about health of their close relatives and follow preventive measures;

- Majority noted that outreach workers are in a better position than health personnel to explain HIV and TB issues. This is a good basis for coordinated activities;
- Almost all respondents are satisfied with received health care services.

5.4. Access to health care: obstacles and motivation

During the research we raised a question of where representatives of the high risk groups can apply to when they have TB symptoms or when they need HIV examination. We had a task to identify places which are most suitable for that, to establish what obstacles they have and what would motivate beneficiaries to seek medical assistance.

Focus-group discussions demonstrated the following:

- The most suitable places where people feel comfortable to apply for medical assistance are partnering NGOs. Here, beneficiaries find understanding, support and help on any health related issues.
- ‘Friendly’ offices, ‘trust’ offices, TB service with friendly doctors and health workers involved in the project were also mentioned by respondents.
- Though clinics, family and local doctors were also named as the first points of contact, respondents also said that they refrain from applying to these institutions because of stigma, long waiting times, financial costs, and other reasons.

The following reasons were noted as obstacles for applying for health care services:

- Personal reasons – fear of diagnosis confirmation, shame, shyness, lack of trust and others;
- Financial reasons – service costs, transport costs, remoteness, medication expenses;
- Lack of knowledge and information – lack of knowledge about the project and provided free services, lack of knowledge about TB and HIV and ways of transmission, mistaken view that TB is incurable and that it can be inherited, and so on.

Focus–group participants listed the following factors contributing to timely care seeking among MARPs and which motivate them to be more cautious about health:

- Received knowledge and information;
- Social accompanying and voucher system of referrals within the project;
- Sincere and friendly attitude of the project staff;
- Coverage of transportation expenses;
- Free of charge diagnostics and treatment;
- Availability of programs such as ‘syringe exchange’ and others;
- Short waiting times and confidentiality;
- Positive examples of successful treatment of people in the group;
- Employment assistance (motivation to be in good health and provide examination certificates if needed);
- Migration (need to have medical examination certificate);

- Good test counseling ‘before’ and ‘after’;
- Family support.

5.5. Effective dissemination of information and additional information

According to respondents trainings, booklets and brochures on TB and HIV are effective tools; however, they also made some comments and suggestions. Thus, they noted that acronyms used in the materials, especially the ones in Tajik, are hard to understand. In general, because of the complexity of Tajik language, it would be more useful to have materials in two languages which would ease comprehension. It was also noted that some beneficiaries are illiterate; therefore it will be good to use more video materials. It was also advised to make more use of TV resources.

As for the additional information, beneficiaries are interested to know more about:

- Other communicable diseases;
- Hepatitis;
- News on TB and HIV diagnostics and treatment;
- ARV therapy;
- Replacement therapy and methadone treatment;
- Psychology;
- Social security and benefits for those with HIV and TB.

Beneficiaries could use this information for themselves and to help others.

6.0. CONCLUSIONS

6.1. Conclusions on knowledge

Among MARPs groups:

- Level of knowledge increased almost in all MARPs groups; however, there are some issues that require serious attention. For example, significant number of people are mistaken about transmission of TB through sharing kitchen utensils;
- Effectiveness of dissemination information using ‘peer to peer’ approach is proved in all groups;
- Basis level of literacy and education of representatives of MARPs groups matters. It has to be taken into account when educational sessions are planned and information materials are developed.

Among outreach and social workers:

- Outreach and social workers – are well informed and interested in the project. They are very important participants of the project;
- High level of TB and HIV knowledge;
- Need and readiness to know more;
- Good communication skills and potential to train other service providers (PHC, Healthy Life Style Centers).

Among health care providers:

- High level of knowledge and skills for work with MARPs population among health providers involved in the project;
- Slightly lower level of knowledge among PHC level health providers.

6.2. Conclusions on attitude change

Representatives of MARPs groups:

- Increased attention to their own health and health of others;
- They feel a need to disseminate information among others and to improve their own knowledge;
- They are willing to help others and to help in reduction of stigma.

Outreach and social workers:

- Understanding of importance of knowledge and acknowledgment of their own input;
- Believe in effectiveness of treatment and need to control the treatment;
- Need to constantly improve knowledge and skills.

Health care workers involved in the project:

- Improved understanding and attention to MARPs groups by health workers involved in the project and program;
- Readiness of health workers to continue work with MARPs groups after completion of the projects and programs.

PHC workers:

- Stigmatization by health workers still remains;
- Discrimination towards MARPs by state bodies is still in place

6.3. Conclusions on behavior change.

Positive developments in behavior change are observed in all MARPs groups. The contributing factors are: educational activities within the project, availability of service packages, and availability of other programs such as ‘syringe exchange’.

As it was noted during focus-group discussions, the following improvements are taking place:

- PWID – use of clean syringes, use of condoms, support and encouragement of risk free behavior, regular examination and more attention is paid to their own health and health of others;
- SW – regular use of condoms, examination and treatment off STIs, motivating partners to use condoms and undertake HIV examination;
- PLWH – following treatment principles, safety at home, care for their own health and health of others.

7.RECOMMENDATIONS

7.1.Recommendations on knowledge:

- Educational activities on specific needs of MARPs to be organized for the representatives of state bodies and agencies;
- Dissemination of TB and HIV information among MARPs shall be continued utilizing ‘peer to peer’ approach;
- It is necessary to conduct trainings for staff of PHC and Healthy Life Style Centers (HLSC) and establish cooperation between them and NGOs working with risk groups;
- Research possibilities to utilize good communication skills of outreach workers for development of similar skills in PHC and HLSC staff;
- Low literacy rate among SW shall be taken into account when trainings are organized and information materials are developed;
- There is a need to broaden the topics of the seminars, and provide outreach workers with deeper knowledge on TB and HIV based on their needs, for which a continuous education system shall be introduced;
- Incentives system for the most active outreach workers and beneficiaries shall be developed. This can include vocational income-job training, which would also contribute to improvement of their life.
- It is necessary to improve provision of national protocols for health care providers on co-infections.
- It is necessary to establish cooperation with the Training Centre for adults on social and outreach work (with the involvement of experienced outreach partner NGOs).

7.2. Recommendations on attitudes change

To support achieved results it is necessary:

- To continue provision of a wide spectrum of TB and HIV services (trainings, social support, counseling, etc.) for MARPs
- To enhance educational activities among national decision-makers in order to more actively lobby interests of MARPs;
- To broaden topics of trainings for outreach workers;

- To improve PHC workers skills on the work with MARPs with the aim of increasing the effectiveness of informational work on HIV and TB.

7.3. Recommendations on behavior change

To support positive developments in this area it is necessary:

- To continue supporting activities of NGOs and centers working with MARPs;
- To continue provision of a wide spectrum of TB and HIV services (trainings, social support, counseling, etc.) for MARPs To assist beneficiaries of the project in improving their living conditions through their involvement in the profitable activities;
- To widely use a potential of outreach workers.

7.4.General recommendations

- Informational and educational activities shall be continued and constantly analyzed through feed-backs. Positive achievements shall be consolidated.
- Good practices shall be constantly supported.
- Sustainability mechanisms shall be developed and introduced. Clear exit strategy shall be developed now and it shall define partners and sources of activities support. Perhaps, there is a need to conduct a seminar on development of exit strategy, which would include measures on post-project sustainability.
- Expand the project activities to other regions of the country based on the results in pilot regions.
- There is a potential for establishment of so called ‘trust houses’. In principle, partner NGOs have established some basis for such work and this is a *significant achievement of the project*.
- Perhaps, there is a need to consider a possibility of creation of public-private associations.
- Obviously, it is possible to conduct exchange of experience among outreach workers and health care providers on communication skills.
- It is important to continue the work with health care providers on communications with beneficiaries and reduction of stigma and discrimination.

8.0. CONCLUSION

- Although in general awareness of the target population increased, there are certain issues that require further work in terms of both quality of conducted activities and trainings of beneficiaries;
- Although beneficiaries and outreach workers changed their attitudes, but the attitude of some PHC level health providers towards MARPs groups has not changed. This fact may affect achievements of the project if not addressed.
- Change of behavior in MARPs groups is obvious, however so far it is supported only by projects and programs. There are specialists at the level of health system who encounter people with TB and HIV every day, however, they are not ready to assist and support them.

The work with the health care system on improvement of the quality and accessibility of the services provided to MARPs population should be enhanced.

- Taking into account significant achievements of the project, well developed strategy, focus on health of beneficiaries and health of their surroundings, it is important to continue work in this direction as the project proved to be very effective.

9.0. ANNEXES

Annex 1.

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5. **HIV and TB TRaC study** evaluating risk behaviors associated with HIV transmission and utilization of HIV prevention and HIV/TB co-infection prevention among PWID in Almaty, Karaganda, Osh, Chu, and Dushanbe. First Round, PSI Research Division 2010
6. **HIV and TB TRaC study** evaluating risk behaviors associated with HIV transmission and utilization of HIV prevention services and HIV/TB co-infection prevention among SWs in Karaganda and Almaty (Kazakhstan), Chui Oblast (Kyrgyzstan), Dushanbe, Vahdat District, Qurgonteppa, Kulob (Tajikistan). First Round. PSI Research Division 2010

Annex 2

GUIDELINES FOR FOCUS GROUP DISCUSSIONS

A. Main Objectives

- a) To assess the level of knowledge, attitude, practice and behavior towards TB and TB/HIV in target groups?
- b) To assess challenges faced by groups of risk when acquiring help and treatment for TB in medical facilities?

B. Target Groups

Focus groups discussions will be conducted with the participation of SWs, PWID, people living with HIV, and migrants.

C. Introduction:

- a) Thank participants for coming to the discussion.
- b) Provide general explanation about the interview in focus group, and also on the objectives of the focus group discussion.
- c) Explain that there will be written notes on discussions.
- d) Assure that the names of participants will not be mentioned in any reports. All responses will be confidential.
- e) Ask for their permission to use a recorder.
- f) Length of the discussion - 60-90 minutes.
- g) To clarify matters, use 'why' question.

D. Questions:

1. Knowledge about TB:

- a) What do you know about TB?
- b) What main symptoms of TB do you know?
- c) How is TB transmitted?
- d) What may happen with the persons who have TB?
- e) What is the treatment period for TB?
- f) Can TB be cured?
- g) What can a person do in order to decrease the risk of transmission of TB?
- h) Have you done any TB test in the last 12 months?
- i) Did you get the results of TB tests?

2. Acquiring help in the medical facility:

- a) If a person has TB symptoms, where should s/he ask for help/advise? Why?
- b) Where would you go for help? Why?

3. Main causes that prevent from acquiring help and treatment for TB in medical facilities:

- a) If you had TB symptoms, what would prevent you from acquiring help in medical facility and start treatment?
 - b) If you wished to ask for help and start treatment, could you do it yourself?
 - c) What do you think about acquiring help and treatment for TB?
4. **Knowledge about HIV:**
- a) What do you know about HIV infection?
 - b) How is HIV transmitted?
 - c) How is HIV not transmitted?
 - d) Is HIV test the only way to find out if a person has HIV?
 - e) Is it possible that a person, who looks healthy, has HIV?
 - f) How often does a person need to undergo an HIV test?
 - g) When was the last time you did your HIV test?
 - h) Did you get the results of your last test?
 - i) What is commitment to ARV therapy?
 - j) What is AIDS?
5. **Knowledge about TB/HIV co-infection**
- a) What do you know about TB/HIV co-infection?
 - b) How does HIV infection impact TB?
 - c) How to diagnose TB among PLH?
 - d) How to treat PLWH who has TB?
 - e) Why it is important to be committed to TB treatment?
6. **Motivations for acquiring help and treatment for TB:**
- a) If you had TB? What would help (motivate) you to come to a doctor and start treatment?
 - b) How important is your health for you?
 - c) What kind of support is important for you to be able to undergo TB treatment? Financial support, support from family, friends, or any other support?
7. **Stigmatization:**
- a) Who could get TB? What kind of people?
 - b) Why people get TB?
 - c) What do you think about those who have TB?
 - d) Do you know anyone who had/has TB?
 - e) Would you continue to be friends with the person who has TB?
8. **Assessing the need in additional information on TB:**
- a) What additional information on TB would you like to get?
 - b) In what language?
 - c) In what format? Video, audio, printed materials...
- E. Conclusion and wrap-up**
- a) Summarize the interview
 - b) Facilitator should review questions and once more read some of the answers. Participants should be given an opportunity to amend their answers and make comments.

- c) Thank participants and reassure them that their responses are strictly confidential, and that information will be used for development of the training program and informational materials on TB.

TEST FOR HEALTH PROVIDERS

1. What is TB?

- a) communicable disease with defined agent
- b) communicable disease with undefined agent
- c) acute virus disease
- d) non-communicable disease

2. How is TB transmitted?

- a) airborne disease
- b) sexually-transmitted
- c) waterborne – while swimming in lake, pool
- d) inherited disease

3. Most frequent TB symptoms (in the order of importance)

- a) prolonged cough with sputum
- b) Sweating, weakness, low temperature
- c) hemoptysis
- d) thirst, dry mouth
- e) diarrhea
- f) high temperature

4. Prevention of spread of TB

- a) early case detection and treatment of TB
- b) organization of systematic controlled treatment
- c) provision of information to TB patients on the appropriate behavioral practices
- d) Isolation of the patient throughout the treatment period
- e) Prescription of low calorie diet

5. How the treatment is conducted?

- a) every time medicine is taken – under control of medical worker
- b) terms and procedures for treatment are strictly followed
- c) drugs are given to the patient
- d) all TB patients are hospitalized until they are fully recovered

6. How do the resistant forms of TB occur?

- a) treatment is not regular and systematic
- b) treatment scheme is amended without authorization
- c) treatment terms are not followed
- d) resistant forms of TB are brought from abroad
- e) resistant forms exist in our environment

7. What is HIV/AIDS: _____

8. HIV is transmitted through:

- a) blood
- b) unprotected sexual intercourse
- c) hand shaking with or through the clothes of HIV-infected person

- d) from HIV-infected mother to baby through breast-feeding
- e) airborne

9. How to find out if a person has HIV?

- a) refer to do an HIV test
- b) refer to do an X-ray test
- c) conduct a general check-up

10. What is a window period?

- a) there is no immunodeficiency virus
- b) there are no enough anti-bodies to immunodeficiency virus
- c) break period in the treatment process

11. Do HIV-infected people are in high risk of getting TB?

- a) yes
- b) no
- c) there is no interrelation

12. Is the combination of TB and HIV dangerous?

- a) yes
- b) not
- c) do not know

If yes, then

why _____

13. What is ARV

therapy: _____

14. What is stigma and discrimination of people with TB and HIV

- a) avoiding communication
- b) being rejected by the society
- c) violation of human rights
- d) methods of treatment
- e) type of consultation

TEST FOR OUTREACH AND SOCIAL WORKERS

1. What is TB?

- a) communicable disease with defined agent
- b) acute virus disease
- c) non-communicable disease

2. How is TB transmitted?

- a) airborne
- b) sexually-transmitted disease
- c) waterborne – while swimming in the lake or pool
- d) inherited disease

3. Most frequent TB symptoms (in the order of importance)

- a) prolonged cough with sputum
- b) sweating, weakness, low temperature
- c) thirst, dry mouth
- e) high temperature

4. Prevention of spread of TB

- a) proactive surveillance and referral to medical facilities of persons with TB
- b) provision of information to TB patients on the appropriate behavioral practices
- c) Isolation of the patient throughout the treatment period

5. What is HIV/AIDS?:

6. HIV is transmitted through:

- a) blood
- b) unprotected sexual intercourse
- c) hand shaking with or through the clothes of HIV-infected person
- d) from HIV-infected mother to baby through breast-feeding
- e) airborne

7. How to find out if a person has HIV?

- a) refer to HIV test
- b) refer to X-ray test

8. What is a window period?

- a) there is no immunodeficiency virus
- b) there are no enough anti-bodies to immunodeficiency virus
- c) break in treatment process

9. Do HIV-infected people often get TB?

- a) yes
- b) no
- c) there is no interrelation

10. If you have conversation with HIV-infected person, you will:

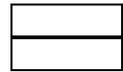
- a) advise to undergo the full TB test
- b) strongly recommend to undergo the comprehensive TB check-up
- c) not talk to him/her about TB tests, since it has nothing to do with HIV.

11. Is the combination of TB and HIV dangerous?

- a) yes
- b) no
- c) do not know

12. What is ARV therapy:

- a) Treatment against TB
- b) Treatment of HIV



TEST FOR BENEFICIARIES

№	Questions and Answers	Mark
1	What is TB?	
	Communicable disease	
	virus	
	Don't know	
2	How can you get TB?	
	From the person who has TB through coughing	
	It is sexually transmitted	
	By using common kitchen utensils	
	Don't know	
3	Main signs of TB	
	Sweating	
	Loss of weight	
	Cough	
	Don't know	
4	Can TB be cured?	
	Yes	
	No	
	Don't know	
5	What is HIV ?	
	Human' body has virus	
	Medicine	
	Computer game	
	Don't know	
6	How to find out if a person has HIV?	
	Undergo a special test	
	X-ray	
	Don't know	
7	How is HIV transmitted?	
	Through using common syringes	
	In sauna or pool	
	Intercourse without using condoms (unprotected sex)	
	Don't know	
8	If a person has HIV, is it obvious from how he/she looks?	
	Yes	
	No	
	Don't know	

Annex 4

GUIDELINES FOR THE IN-DEPTH INTERVIEW WITH PLWH HAVING TB

TB patient №

General information

1. Date:

2. Interview started at (time):

Interview ended at (time):

3. Location:

4. Name of interviewer:

5. Specifications of the participant:

6. Current status:

7. Gender:

9. Age:

10. Region/district:

11. Marital status:

12. Education:

13. Profession:

14. Family situation:

Informed permission was granted *: _____ (facilitator's signature)

* Facilitator should explain to the participant what interview objectives are and ask for written permission to conduct an interview. If the participant agreed to take part in the interview, the facilitator can put his signature here.

Questions:

Below is the list of open-ended questions for interviews. It is important to ask all these questions, however, their order and format may be amended. You may ask additional questions to clarify the information. It is possible that the participant answers some of the questions beforehand (while answering other question). In this case, you don't need to ask that question, since you already have the answer. Make notes during the interview. Note the questions that you have asked (the way you asked them, the order, and any additional clarifying questions) and his/her answers. You may also record the interview, but you need to ask the participant for permission.

1. When were you diagnosed with TB?
2. Are you still going through the treatment? If not, when did you finish the treatment?
3. For how long have you been treated? Were you cured? Do you still need to visit health facility for check-up and/or treatment? If yes, how often do you need to visit and what kinds of tests are conducted? Are you still taking medicine/receiving treatment, because you had TB? If yes, what kind of medicine/treatment?
4. What are the main signs of TB? _____
5. How did you get TB? _____
6. Can TB be cured? IF yes, what kind of treatment is necessary?
7. When you became ill, where did you first go for help/advise? What was the time period between you feeling ill and actually asking for help?

8. Where (what facility) were you told that you have TB and who told you that? What was the time period between you feeling ill and becoming diagnosed with TB? _____
9. How were the TB tests conducted?
10. What was the time period between you being diagnosed with TB and actually getting TB treatment? (If the time period is more than a week, ask about the reason for that) _____
11. What kind of treatment did you get? Where were you treated (did you buy drugs in the private pharmacy, were you hospitalized or treated in the polyclinics, were you first in the hospital and then in other medical facility, or you were in the hospital all the time, etc.) ?

12. If the respondent was hospitalized, ask: «How long were you hospitalized for? Were you comfortable with being hospitalized? If yes, explain why. If not, would you prefer to be treated differently? If yes, how would you want to be treated? »

13. Was the staff of the facility, where you were treated, insisting on the importance of completion of treatment in order to cure from TB? IF yes, how did they do that?

14. Are you satisfied with the information on TB and treatment you received from medical staff? What kind of information on TB you received from staff (example, explanation, brochures, DVD, etc.)? Are you satisfied with such support from the medical staff?

15. Do you know why it is important to continue and complete TB treatment? If yes, explain why? Who explained you that?

16. Do you know why it is important not to stop the treatment? If yes, explain why? Who told you that?

17. Have you ever missed taking drugs during the period of TB treatment? If yes, explain why? Who supported you during the treatment? Who took care of you, when you were taking medicine?

18. Did you tell anyone (family members, friend, community members, colleagues, etc.) that you have TB? If yes, whom did you tell and what was there response?

19. Do you have or did you have any problems in your family, community or at work because people found out that you have TB? What kind of problems? Were/are you discriminated because people found out that you have TB? If yes, tell us about it. Did you or do you get any support from people, who knew that you have TB? Did you get any social assistance e.g. from community, NGO, government)? If yes, what kind of assistance?

20. Did you have enough money to receive necessary help and treatment? What services did you have to pay for as TB patient (e.g. X-ray, hospitalization, drugs, transport, etc.). Did you have sufficient money for that? If not, do you have any suggestions on how to decrease these costs? Did you have to borrow money to pay for treatment?

21. How much time did/does it take you to travel from your residence to treatment facility? (If the respondent has not mentioned the facility yet, please ask for the name, type and location of the facility). How did you travel to the treatment facility? Were you able to visit this facility on

regular basis (both in financial and geographical terms)? If not, could you suggest how to address this issue?

22. If the respondent has a family, ask if they were/are worried that s/he had/has TB? Do you have any suggestion how to ease their suffering?

23. Did your HIV-status have any impact on diagnosis and treatment of TB? (Did you have any doubts about asking for help, did you refuse any treatment, were you afraid that your status would be revealed?)

24. Were you satisfied, in general, about treatment and care (including 2 months hospitalization) that you have received? If not, what changes would you like to suggest?

There are a lot of questions to ask. Interviewers should transform interview into conversation about looking and asking for medical services. Give the respondent an opportunity to tell his/her story, and not just read your questions one after another.

Thank you very much!

Annex 5

BRIEF INFORMATION ABOUT RESPONDENTS OF IN-DEPTH INTERVIEW

Patient #1

It is a man, 27 years old, who lives in Dushanbe city and has secondary special education. He works as car mechanic and defines his family as underprovided. The interview with him was carried out in the office of “SPIN plus” NGO. He thinks that he has got infected with tuberculosis in the prison in 2010. He notes that has received treatment and at present continues to treat himself. 2 weeks have passed from the moment of onset of first symptoms (he knows TB symptoms – prolonged coughing with spitting, high temperature, asthenia) till visiting medical unit of penitentiary institution and it took 4 days after the diagnosis to start the treatment. He notes that in order to set a diagnosis an examination of sputum and X-ray of chest was carried out. He has received free treatment, firstly – treatment of Plevritis within 2 months, then – DOTS in the prison. He notes that he was treated well; however the sanitary and hygiene conditions were bad. Medical personnel talked with him about tuberculosis and importance of treatment. He assumes that if the treatment would not be carried out, then the bacilli could become resistant to treatment.

He notes that during the period of prolonged coughing he felt that people didn't like it, but he didn't noticed a stigmatization in open form. Also, the patient said that the treatment was free and he didn't borrow any money.

The patient noted that visiting polyclinic was not problematic for him, since he lives near by it.

Patient #2.

This respondent is a man of 31 years old, single, lives in Dushanbe city, has secondary special education, works as driver, and estimates his family situation as underprovided. In the anamnesis has a fact of being imprisoned from 2001 till 2004. He assumes that has got infected in the prison, when visited his TB-infected friend, although the diagnosis was made in 2009. He notes that in his opinion the main and first symptom was blood spitting that forced him to ask for medical treatment. Firstly he applied to a general rural hospital (he lived in Russia at that time), where his blood spitting was stopped and he was transferred to TB hospital. He thinks that 2 weeks had passed from the moment of disease onset till formulation of the diagnosis. In TB-hospital he was registered as homeless person and received treatment within national program, i.e. for free. At present he takes treatment diligently and thinks that the treatment in Tajikistan is better and tablets are of higher quality and he takes them systematically and regularly. He is very grateful to “SPIN plus” that they have supported him in difficult times, sent him to hospital to have a treatment and even bought him medicine and other needed things at their own expense. He thinks that in the hospital they explain everything, but he already knows many things since he passed some training. He understands that if he will not treat himself constantly and

systematically then the bacilli will mutate and become resistant to treatment. He didn't borrow any money. Sometimes his sister sends money from Russia.

Patient #3.

It is a man of 35 years old, lives in Dushanbe city, married, has a secondary education, he estimates his family situation as a family with average income. First time he was diagnosed in 2005, but he didn't treat himself properly, he had a break in treatment (used drugs), then in 2008 he started treatment again but also didn't finish it. In 2009 a TB diagnosis was done again. He thinks that he caught cold when he was in prison; cough, sputum and temperature appeared. He applied to medical unit and was examined (X-ray, sputum examination), the diagnosis was made immediately. The treatment was started 2 days after – diagnosis in the hospital during 6 months (approximately), then he received treatment in Khorog (about 3 months) in TB dispensary. Third time he was treated through “SPIN plus”. At the same time he wanted to quit using drugs – he was in resuscitation department. There doctors detected pleuritis, tuberculosis and transferred him to TB-dispensary and he started the treatment. Later he was prescribed to complex therapy – ART and TB. He took these medicines during 8 months very carefully. During the period of taking there were drug side effects such as anxiety dreams, depression, etc. But he was explained that such things happen and he calmed down. Now his condition is not bad.

Patient #4

It is a man of 36 years old, he lives in Khatlon province, single, has secondary education, and belongs to the groups of PWID, PLWH, and TB. The diagnosis was made 6-7 months ago. He notes that received treatment for several months and is not being treated at the moment, he thinks that he recovered from TB. At present he does not take any anti-TB medicine, but on the other hand he continues ARV-therapy. He names such symptoms of tuberculosis as cough with elution of sputum, weight loss, and bad sleep. He supposes that he got infected because he visited his TB-infected friends in TB-hospital. Regarding the curability of TB he thinks that this disease is curable if treated in proper time, systematically and carefully. People in the NGO paid attention to his general state and escorted him to get examined (X-ray, examination of sputum), where TB-positive diagnosis was made. The treatment was long up to 6 months and free. Staff members of “SPIN-plus” working with PWID were very helpful to him. He was treated at home with the support of outreach worker. This patient notes that outreach workers were more active than medics in the issue of TB awareness. Namely an outreach worker explained him that if he wouldn't treat himself carefully and according to the schedule, then these causative agents will become resistant to medicine and it will be hard to recover. This patient also notes that the treatment was free of charge and he did not have to borrow money for the treatment. There was no problem for him to go to city TB-dispensary in Kulob. The patient notes that he is satisfied with the treatment in general.

Patient #5.

This is a man, 29 years old, has one child, lives in Khatlon province, has secondary education, has no profession.

There is information in anamnesis about his mother who had TB. He was the one who stayed with her in the hospital. He was 7-8 years old and does not remember many things. His diagnosis was made in 2010. He is not being treated at the moment. He used to receive treatment for one month in state hospital, then 15 days more. Then he stopped the treatment and went to Dushanbe city. He notes that 10-12 days passed from the moment of deterioration of condition till making a diagnosis, and after the diagnosis was made the treatment started almost immediately. The patient thinks that tuberculosis is curable if one receives treatment regularly. He treats himself at home during the period of one month. Then he went to Dushanbe. Regarding his HIV-status he speaks unconfidently, he got tested twice, the analysis was questionable, but he didn't wait for the confirmation and now he doesn't know his real status. Regarding the importance of observance the adherence to the treatment he is informed insufficiently and didn't give any answer. He notes that lives far from medical unit, and it is not convenient for him to visit it since he has to spend 2 somoni each time. In general, he thinks that TB-treatment medicines were effective.

Patient #6.

It is a man, 34 years old, lives in Vahdat, has secondary education, his profession is – worker, he is married, has 2 children, he estimates the economic situation of the family as having income less than average level. He notes that the diagnosis was made in 2008 in Moscow. He is not being treated at the moment, since according to him the treatment is finished. He notes that first symptoms were asthenia, hyperhidrosis, weight loss, and the general condition dramatically was worsened. He didn't actually notice coughing. At that time he was working in security service, used drugs, and didn't pay attention to his health. Then he decided to get examined in private clinic in Moscow, where TB-positive diagnosis was made within 3 days. Pleuritis was diagnosed and he was treated in Machevon for approximately 1.5 months, then continued the treatment at home. He continued to take tablets for very long period. Hospital personnel explained him that the treatment must be long-lasting and without any break. Doctors said that if one did not treat himself properly, then the recovery might not happen. And he does not want to infect other people and tries to recover completely. It was hard in financial terms. The operation cost was 500 USD, all procedures required money. However, in TB-dispensary he didn't pay, the TB medicine was free of charge, but other medicine he had to buy. The patient notes: "If I go on behalf of NGO – then it is free, but in this case I had to sell a bull-calf and give out the debts for the treatment. The family knows about my disease, they are worried. I try hard not to disappoint them and treat myself accurately."

Patient #7.

It is a man of 29 years old. He is single and lives in Kulob. He has secondary education and no profession. He estimates his family economic situation as having average income. The diagnosis was made in 2010 for the first time. He has been receiving the treatment for the period of more than one year. And now he continues the treatment. He visits doctor once a month. He felt himself bad a year ago (asthenia, hyperhidrosis, coughing) and then applied to “Anis” (he is PWID) and they immediately sent him to get examined in TB-dispensary and there the diagnosis was made. 5-6 months passed from the moment of making the diagnosis till the beginning of treatment, since he thought that he has unserious disease. Then he started the treatment – he was in a hospital for one month, then was taking tablets for 3 months. He thinks that one can be cured if one takes medicine on continuous basis. The patient thinks that it is enough to take medicine from 3-6 weeks. The patient was treated in hospital and thinks that the treatment was not bad – injections, tablets, procedures. The patient also notes that there were conversation on importance of continuity of the treatment, in other case the microbes might “get used” to the medicine and there would be no effect of taking them. Unfortunately, he had breaks in the treatment, since he is PWID. His family knew about his status and supported him. Regarding financial issue, he noted that the medical unit is far away and he needs 2 somoni for the transport every time. “I didn’t hide my status. Regarding the treatment – I am satisfied.”

Patient #8.

It is a man of 38 years old, widower (his spouse died two years ago), has three children. He is PWID, PLWH, TB. He didn’t test his children on HIV and TB. He has secondary education. Answering the question about his profession he said that he is a poet.

He has been using drugs since 1993, firstly light ones, then – injection. The TB diagnosis was made in 2012. He felt pain in chest, pleuritis and TB were diagnosed. The patient is acquainted with general symptoms of tuberculosis: he names continuous coughing with elution of sputum, hyperhidrosis, weight loss, asthenia, etc. He thinks that TB is curable if timely treated and without any gaps. He doesn’t miss his medicine takings. He applied to the medical institution independently, since there everybody knows that he is on behalf of “Anis”. X-ray was done in TB-dispensary, sputum was examined, Dr. Olimov examined the patient and made a TB diagnosis. The treatment started next day, the treatment was free of charge. He was also an outreach worker of “Jovidon” NGO. He didn’t buy medicine. He was in DOTS program. In the beginning he received medicine for 4 months. He took the medicine by himself, without any control of medical worker. At the very beginning was treated in private clinic for one week. He didn’t stay in TB-dispensary, since because of the status the immunity was weak. At present he receives treatment at home and visits Dr. Olimov every 10 days. He didn’t hide his status and thinks that he is being well treated.

Patient #9.

It is a man of 39 years old. He is married and has secondary special education. His profession is electrician. After return from Russia when forced respiration, continuous coughing were troubling him he applied to local hospital. The diagnosis of bronchitis was made. Gradually his condition was worsening, the treatment didn't help. His temperature was 39 and higher. The repeated x-ray showed pleuritis. And according to him 3.5 liters of liquid were pumped out. The TB diagnosis was made. By the advice of phthisiatrician he received treatment during 16 days, and then 10 more days in private clinic. In total the whole course of treatment was 7 months. The patient didn't tell us the main symptoms of the disease and couldn't exactly name the possible reasons of infection. But he thinks that the disease is curable if a treatment is carried out in proper time and medicine is taken frequently. When our patient became ill he applied to local hospital, where they couldn't make a correct diagnosis. Then he applied to Mahmad and he took him to Macheton to take an x-ray and only then the TB was diagnosed. With this diagnosis he was treated in private clinic. As it was noted by the patient, 1.5 months passed from the moment of disease onset till the establishment of diagnosis. At the present he takes tablets at home. He notes that he was told the most clearly about this disease in municipal TB-dispensary of Dushanbe. They explained how to take medicine, what to wash down with, and why it is important not to interrupt the treatment in order to recover completely. His family knew about his diagnosis, they displayed understanding, and he tried to treat himself accurately. The patient thinks that there were some financial difficulties, but his brother helped him. Though TB medicine was free of charge, they had to pay for all other medicines, services, diagnostics, etc.

Patient #10.

It is a woman of 30 years old. She is married and has secondary education. She is employed as a seamstress. She was infected in the winter of 2011. She suffered from coughing, high temperature, and forced respiration. According to her, firstly she was told that it is pneumonia, then pleuritis. She was hospitalized to Macheton for 2 months. According to x-ray, there are improvements in the process. She continues the treatment. She knows the answers to the questions on TB symptoms – long-lasting coughing with sputum, asthenia, hyperhidrosis, etc. She notes that this disease is curable if a person adheres to the correct treatment in proper time and frequently takes the medicine. Good nutrition is important. She notes that they couldn't make a correct diagnosis at the beginning. They thought it was influenza. After she applied to Shahlo, an outreach worker, who accompanied her. The diagnosis was made and the treatment started immediately. Medicine is being brought to her by medical sister who explains how to take them correctly. Her family members support her, particularly her husband. He is also a staff member of “SPIN plus” NGO in Vahdat.

ANNEX 6. RESULT OF TEST FOR BENEFICIARIES (MIGRANTS N19)

Nº	Questions and Answers	Mark
1	What is TB?	
	Communicable disease	15
	virus	1
	Don't know	3
2	How can you get TB?	
	From the person who has TB through coughing	13
	It is sexually transmitted	1
	By using common kitchen utensils	8
	Don't know	1
3	Main signs of TB	
	Sweating	3
	Loss of weight	2
	Cough	9
	Don't know	5
4	Can TB be cured?	
	Yes	13
	No	1
	Don't know	5
5	What is HIV ?	
	Human' body has virus	13
	Medicine	1
	Computer game	
	Don't know	5
6	How to find out if a person has HIV?	
	Undergo a special test	11
	X-ray	1
	Don't know	6
7	How is HIV transmitted?	
	Through using common syringes	13
	In sauna or pool	2
	Intercourse without using condoms (unprotected sex)	11
	Don't know	4
8	If a person has HIV, is it obvious from how he/she looks?	
	Yes	2
	No	11
	Don't know	6