Qualitative research among most at risk populations for TB in Health Outreach Project pilot sites in Kazakhstan

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Table of Contents

Abbreviations and Definitions

DOTS – Internationally recommended WHO strategy to fight TB
FGD – Focus Group Discussion(s)
HIV - Human immunodeficiency virus
IDI – In-depth Interview
IDU – Injection drug user
MARP – Most at risk population
MSM – Men who have sex with men
PLHIV - People living with HIV
SW - Sex worker
TB – Tuberculosis
TB infection – presence of *Mycobacterium tuberculosis* bacilli in the body, not active disease

1. Background

Since 1997, USAID has focused considerable resources on addressing the HIV and TB epidemics in the five Central Asian Republics (CAR). All countries in CAR now have national HIV/AIDS and TB control programs supported by the governments and by international donors such as USAID, the US Centers for Disease Control (CDC), the World Health Organization (WHO), and the Global Fund to Fight AIDS, TB and Malaria (GFATM), among others. These national programs seek to address HIV and TB among the general population and most at risk populations (MARP), including: injecting drug users (IDU), sex workers (SW), migrants, men who have sex with men (MSM), prisoners, and people living with HIV (PLHIV).

The new "Health Outreach Program", funded by USAID and implemented by the Health Outreach Program Consortium (PSI, Project HOPE, AFEW, and the Kazakh Association of PLHIV) started in 2009. In the region with one of the fastest growing HIV/AIDS epidemics in the world, the Health Outreach Program Consortium targets MARPs most likely to contract or transmit HIV and TB: IDU, CSW, migrants, MSM, prisoners, and PLHIV. Risk for TB infection is higher among IDU, prisoners and migrants, but is particularly dangerous for PLHIV. Thus, TB interventions will specifically target these four groups in Kazakhstan, but will also include general TB/HIV co-infection prevention messages in outreach to MSM and SW.

A formative study was designed to be conducted among MARPs to obtain information about each group's knowledge, attitudes and practices on TB and identify key barriers and determinants for seeking care and getting TB treatment. The result of the formative research will be used for revision of the Kazakhstan TB National Communication Strategy, revision and development of an education program for TB outreach among MARPs and development of information, education and communication (IEC) materials.

2. Objectives of this study

The objectives of this study were to:

1. Document the current level of knowledge about TB among MARPs in pilot sites
2. Identify factors impeding or contributing to care seeking and getting TB treatment
3. Identify the above-mentioned factors covering different population subgroups, including both genders, as well as rural and urban populations.

3. Methods

A mixed methodology and Formative research protocol for Focus Group Discussions (Annex 1) and In-depth Interviews (Annex 2) were followed to conduct this study among MARPs in Almaty and Temirtau (Karaganda Oblast), which are Health Outreach Program pilot sites. In compliance with the Protocol, Almaty was selected as a large city

with representatives of all target groups, and Temirtau is a provincial city situated far from Almaty and could be referred to as a rural setting having two combined groups of MARP representatives – IDU and PLHIV – impacted by TB. Qualitative focus group discussions (FGD) and in-depth interviews (IDI) were conducted to determine factors impeding or contributing to care seeking and getting TB treatment.

Trainings for facilitators of FGD and IDI were conducted prior to research activities. Twelve representatives from local NGOs working with different groups of MARPs in Health Outreach Program pilots (including three PSI staff persons) were suggested by PSI to participate in the training in Almaty. Another training was held for 6 members of NGO in Temirtau.

The whole research team participated in two one-day trainings, which were facilitated by the Health Outreach Program Program Manager and TB specialists (Project HOPE). It covered introductions to the research questions, methodological characteristics of FGD, reasons for the choice of this method for the questions to be investigated, as well as content and use of the discussion guidelines.

3.1. Research Area and Participants of Focus Group Discussions

The qualitative research discussed in this report was conducted in Almaty and Temirtau in February 2010.

Local NGOs were included in the research process to encourage more accurate responses from MARP group representatives, as they have greater trust in people who have already worked with them. The research team for each FGD consisted of a moderator and assistant.

FGDs were conducted in private settings in hotels and NGO offices, in Russian, as almost all respondents could speak and understand the language well.

3.2. Research Protocol and Inclusion Criteria for Participants of In-depth Interviews

An in-depth interview protocol adapted from the Project HOPE migrant's study was used in this study. All interviews were conducted by two trained NGO facilitators. Informed consent was obtained from all participants at the beginning of each interview. The aims and objectives of the study were clearly explained, and participants were remunerated for their time.

Current and former TB patients among PLHIV were identified through the local NGOs. Interviews were conducted to identify any barriers encountered in obtaining TB diagnosis and treatment. Criteria for inclusion were PLHIV who have or had TB during the previous two years.

All interviews were conducted by trained outreach workers. The aims and objectives of the study were clearly explained, and participants were given incentives for their time and participation: in Almaty all participants, as well as moderators, were given cell telephone cards, and in Temirtau the request was to provide participants with product packages.

4. Data Analysis

4.1. Topics of Focus Group Discussions

Discussion guidelines for the FGD are provided in Annex 1 of this report. These discussion guidelines were used in the training as well as during the FGD. The topics and general questions covered were:

1. Knowledge about TB
2. Care-seeking behavior
3. Barriers for seeking care and getting TB treatment
4. Motivators for seeking care and getting TB treatment
5. TB stigma and discrimination
6. Needs for additional information on TB

4.2. Focus Group Discussions

The analysis and results below are presented in accordance with the list of questions discussed during the focus group sessions, with answers sorted by the type of MARP. The answers were combined and arranged by frequency of occurrence. Some of the points in the lists were said only by one participant. We attempted to keep reported answers in line with respondents' vocabulary and specificity of speech.

A total of eleven FGD were conducted among MARPs who are currently being treated or have been treated for TB, to investigate the determinants of adherence to diagnostic procedure and treatment for TB.

Participants of FGDs were the following representatives of most at risk populations (MARP): 30 injecting drug users (IDU), 13 sex workers (SW), 14 men who have sex with men (MSM), and 19 people living with HIV/AIDS (PLHIV). Two members of the group were from Temirtau (12 IDU and 9 PLHIV), and the rest were from Almaty.

Table 1. Number of focus group discussions and participants, by MARP type and location

MARP type	**No. FGD conducted**	**No. participants, Almaty**	**No. participants, Temirtau**	**Total participants**
PLHIV	2	10	9	19
SW	3	13	0	13
IDU	4	18	12	30
MSM	2	14	0	14

Total		**55**	**21**	**76**

Knowledge about TB:

i. What do you know about TB?	
PLHIV:	*SW:*
• serious, infectious and droplet transmitted disease; • depends on immunity; • it's called bacillus Kochii and it cannot be destroyed • smoking provokes TB; • TB can be different: bone, blood, pulmonary tuberculosis.	• there is an open form which is incurable and a closed form which is curable. Lungs disease. Early stage is curable, advanced is not. Open form is dangerous; • lungs breakup, sick man doesn't live long. Person can die; • one withers like a tree, pallor, coughing, skinny; • affects lungs and liver.
IDU:	*MSM:*
• Deadly disease.	• it's droplet transmitted disease; • related to lungs; • it's such a disease, if one has it, he (she) knows for sure; • it's a harmless disease, it's same as cough.

As it can be observed, all groups of respondents have various, incomplete and mostly inaccurate information about TB. In general, PLHIV and SW drew the biggest picture of the disease. There were a few people in the MSM group that thought that TB is not a serious disease and not distinct from a regular cough.

ii. What are the most important signs of TB?	
PLHIV:	*SW:*
• cough; • sweats, normal and extra sweats; • fatigue; • sudden weight loss; • fever; • one might feel nothing.	• cough; coughing up blood; • fatigue, general state like a drunk man; • one losses weight skinny person; • sweats; • fever; • Depression, first stage – weak cough, advanced stage – cough with blood. • fatigue, pain occur, immunity decrease; coughing, appetite loss,

	headache, stress; weight loss, mental disorder; nausea;
IDU:	*MSM:*
• cough, coughing up blood; • sweats; • weight loss; depletion; • fever; • I don't know.	• cough; coughing for more than 3 weeks; • sweats • one feels bad; • weight loss; • urinary incontinence.

More or less, the informants were aware of the most important signs of TB, excluding the MSM group, who didn't mention fever, fatigue but urinary incontinence which is false. Notably, SW group members knew something about the stages in TB.

iii. How is TB transmitted?	
PLHIV:	*SW:*
• through droplets; • if one smokes the same cigarette with a sick person; by (sharing) a mutual dish; • if one is in the same room with person who has TB, for example, same cell in prison; • self-suggestion: if one is scared, he (she) won't escape this disease.	• through air; <u>only</u> through air; through droplets and breath; through cough; • through dishes, things and bed; • through saliva; • through kisses; • through a syringe.
IDU:	*MSM:*
• through droplets; through air; • through needle or blood; • cigarettes, mutual dishes; • sexually; • this disease is not transmitted after one is 35 years old; • genetically transmitted; • everything depends on the stage.	• through droplets; • sexually; • through kiss; • through sputum; • from human to human; • mouth-to-mouth ventilation.

General awareness of the TB's droplet transmission together with versions of contact, sexual, genetic and blood ways of transmission let us believe that all groups require more information on this topic.

iv. Is TB curable?	
PLHIV:	*SW:*
• yes, if in time; • it's curable only at an early stage; • no, Bacillus Kochii can't be killed.	• yes; • no.

IDU:	*MSM:*
• yes; • one can only suspend it; • Probably no.	• curable only at an early stage; • one can suspend it; • no; TB is incurable; it's impossible.

As we can see, the majority of our respondents believe that TB is curable, but there were a few in each group, who think the opposite, that TB cannot be cured.

v. How long is TB treatment?

(For ease of analyzing answers to this question, we decided to use categories.)

The majority suppose that treatment length is from 6 to 24 months, with 1 year being the most frequent answer (SW, IDU). The majority of PLHIV believe that it takes 6 months (e.g. "2 months in hospital, 4 in outpatient department") while MSM have various opinions, 3-5 years together with 3-6 months or just "very long". As mentioned in the previous section, there were some who strongly believe that TB is not curable ("What is treatment for, one won't get cured anyway") and participants mentioned money as an important factor for receiving treatment.

Care seeking behavior:

i. If somebody has TB symptoms where should he/she go for help/advice?

The most common suggestion was to go to the PHC and see a physician. The second place answer was to go to the TB center. Participants from the SW groups suggested going to a private clinic and mentioned again that money matters. One person each out of two IDU groups proposed to get advice from relatives. PLHIV mentioned fluorography (x-ray) and MSM would visit a healer or even seek no advice ("I'd rather shoot myself"). These answers were very rare but still should be noted.

ii. Can he/she go to PHC facility or TB centers?

All participants who were asked this question (PLHIV, IDU, MSM) answered positively. MSM even mentioned that going to PHC or TB centers is free of charge.

Barriers for seeking care and getting treatment:

i. I would like to find out - if you had TB, what would prevent you from seeking care and getting TB treatment?

Surprisingly, almost nothing would prevent people from seek care and getting treatment, especially in the MSM group ("I think a person doesn't have to be shy"), however one of them argues his answer by the idea that TB is harmless. The PLHIV group listed the following barriers:

- family circumstances;
- laziness;
- lack of time;
- fear;
- negligence of medical staff, their rudeness.

The rest of the sample didn't participate in this discussion.

ii. If you wanted to seek care and treatment, would you be able to do so by yourself? Is anyone else connected to your seeking care and treatment?

In all cases the answer was yes, with general emphasis on family and friends as the main source of support. The statement that he/she would do it by him/herself was mostly given by participants of IDU and SW groups. Probably, this category of people feels the most independent and isolated ("I wouldn't tell anyone and would do everything by myself", "there's no one I can rely on"). When answering this question, the following thoughts appear (SW): "It's necessary to pay for treatment; without money one won't get treatment; treatment is always hampered by money; with money I will be cured; if one has money it's not a problem". Financial concerns most probably can prevent these people to seek care and treatment ("They accept even without money but won't start the treatment"), as they may not seek services if assuming that a lack of money is a barrier.

iii. How would you feel about going to seek care and treatment?	
PLHIV:	*SW:*
• OK; • everybody requires support from family; • one can't consume alcohol; • pills curing TB harm liver, it's possible to destroy liver.	• it's not a problem today to receive some treatment; • I will immediately seek care; • I think they will treat properly and well; • staff in TB center understands better; • I'd receive paid treatment. Paid treatment was always better than free - one's treated good and better looked after.
IDU:	*MSM:*
• fear; • discomfort, anxiety; upset; • normal; as a sick person; • lousy; • I've never thought about it.	• it's serious illness; • anxiety; • I would feel nothing; as regular illness; • humiliated; shame.

The most concerned groups of people are IDU and MSM reporting that they would feel badly by experiencing fear, anxiety and even shame when seeking care and treatment. This group out of the sample might be considered as the most vulnerable on this issue.

In general, barriers for seeking care and treatment can be divided into two types: internal and external. Internal barriers include personality issues: motivation, emotions, feelings, etc. (laziness, fear). They may be easier to cope with. External barriers can include family, society, conditions, circumstances, attitudes, etc. (negligence of staff, lack of time). In this study, we observed all these barriers and would suggest focusing on use of interventions that will address both types of barriers.

Motivators for care seeking and getting TB treatment:

There was a two-part question asked to participants of FGD:

iv. If you had TB, what would motivate you to seek care and get treatment? Is seeking care and treatment important for you?

Seeking care is important for all respondents. SW and MSM even emphasized how important their health is for them. PLHIV displayed responsibility and thoughtfulness in this question ("Caring for family and friends in order not to infect them". "…It depends on a person's understanding; if one isn't out of one's head, he/she will see a doctor") probably because they had already confronted their struggle with the HIV virus.

v. What kind of support would be helpful for you to seek treatment? Financial, family, friends, some kind of incentive?

Support from family and friends would be the most helpful element for the treatment seekers according to the opinion of our respondents. Financial support is sufficient for the majority as well. "My health concerns only me" and "I don't need support" said a few representatives of SW, IDU and MSM. PLHIV highlighted understanding and positive attitude of medical staff, proper conditions in clinics, reasonable nutrition, support from government including social packages, and support from psychologists. Consultations and volunteers' involvement were suggested as a possible means of support as well.

Stigma and discrimination:

i. Who can get TB? What kind of people?

Everyone can get sick, was opinion of the majority. PLHIV mentioned immunity as a great factor in getting sick with TB. According to their opinion, together with SW, homeless people and those in the lower socio-economic class are considered to be those who can get TB. Other answers: smokers and drinkers, those who don't eat well, those who are located in unventilated rooms, those who are in prison or recently released, those who spend a lot of time in the cold (mostly by SW), pregnant women, those who work hard (PLHIV), and those who do not practice safe sex (MSM).

ii. Why do people get TB?

People get TB because of their life conditions: e.g. "style of living", "nutrition", "ecology", "and unsanitary conditions", "cold and dampness" (IDU, PLHIV). They supposed that bad life conditions could weaken the body and make it more vulnerable

for TB. Some respondents thought that taking care of one's health could prevent getting TB and one also gets TB because of one's attitude ("negligence to one's health"). On the other hand, some people from the target groups believed that there was something fatal in getting TB when talking about one's "destiny" or bad luck (IDU); of people who infect each other; and because of self-suggestion. Nobody mentioned possible ways of TB protection and some suggestions were based on a lack of awareness on means of TB transmission

iii. What do you think about TB patients?

The majority of the respondents feel compassion and sympathy ("Poor devils, they have bad luck"). Many people also think that TB patients need attention and support ("They should be supported and helped"). "There are normal people, they mustn't be stigmatized" said one participant from IDU group. In general, other members of that group showed tolerance to such people admitting that they are just like others. On the other side SW and MSM are more skeptical and tough in that sense by feeling fear ("One has to fear them, they can infect anyone anytime") and even disgust ("they are freaks", "they are on treatment for 10 years and expectorate", they need "separate housing accommodations").

iv. Do you know somebody with TB?

At least one person in each group knew somebody with TB, specifying that it's a relative or friends or someone who died already. One IDU and the majority of SW did not know a person who had TB.

v. Would you be friends with someone who has TB?

The majority said that they would be friends with someone who has TB. A few respondents from the IDU group mentioned close relationships, spiritual support and friendships, the rest said that they will support and interact as usual but with precautions such as not to smoke the same cigarette, not to drink from the same cup, wear a mask and etc. Representatives from MSM and IDU groups said no, or to be friends only by phone. PLHIV representatives were more thoughtful and reflective: "One should ask which form of TB he (she) has, if the closed one, I can always stay friends". "It depends on person's attitude: if he/she wants, he/she will stay friends".

We noted how people are mistaken about TB signs, transmission, etc. which may result in some negative attitudes and behavior toward the TB patients. More information is required concerning this topic.

Needs for additional information on TB:

i. What additional information about TB would you like to receive?	
PLHIV:	*SW:*
• easier and more accessible form of	• how TB occurs? what are the

information.	special and unique signs of TB? • what to do in order not to get sick? • How to protect oneself from this disease?
IDU:	*MSM:*
• What kind of treatment against TB exists? How long is the treatment in order to cure? Is TB curable? Is there such a treatment which cures one for good? • What is the TB situation in Kazakhstan?	• information about how dangerous TB is (pleurisy and TB), • prevention and commercials; • how to recognize TB.

ii. In what language?

Information is required in both Russian and Kazakh languages. In Kazakh, especially for the SW group because facilitators mentioned that sometimes they had to translate questions for the focus group discussion into Kazakh. All groups of MSM and one group of PLHIV from Temirtau said just in Russian.

iii. In what form would you like to receive this information?	
PLHIV:	*SW:*
• video, short videos instead of commercial on TV; • brochures; • seminars and trainings.	• video materials; • printed materials (posters, brochures); • audio materials.
IDU:	*MSM:*
• video on computer and TV; • printed materials with illustrations, booklets, comics; • seminars for population; • all types of information; • crisis hotline; • more focus groups with discussion.	• printed materials; • any materials.

4.3. Analysis of In-depth interviews

In-depth interviews with PLHIV TB patients were analyzed to identify themes such as lack of money to pay for private consultation, the economic need to keep working, the lack of knowledge that TB could be cured, or fear of community stigma and being socially ostracized. In the data analysis, the terms and concepts from the participants' own phraseology was used to distill themes. Themes regarding reasons for PLHIV delaying seeking TB diagnosis and treatment were identified.

Eleven one-hour in-depth interviews were conducted among PLHIV who had previously received or who were currently on TB treatment in two sites: Temirtau (4) and Almaty (7). Six of them were injecting drug users (IDU).

The sample consisted of 11 people (4 females = 36 %) with the age range 27-54 years old (Median = 37.82).

Marital status and education: the majority - 8 out of 10 (one didn't indicate her status) is single including one divorced. 46% (5 participants) of the entire sample are graduates of high school, 27% obtained specialized secondary education and 9% (one person) has a higher education. The rest 18% (2) didn't complete high school.

Out of eleven participants, seven (64%) were co-infected with TB and HIV, and the rest were registered as TB patients. Among the 5 people (46%) who are still on treatment for TB, three reported that they are being re-treated. Five respondents had a relapse.

The interviews were carried out in Russian and translated into English for analysis. The interviews were conducted in February 2010.

4.4. In-depth interviews

TB related knowledge, attitudes, practice and behavior

Signs of TB (in the brackets are the amount of participants, out of eleven, that mentioned the signs):

- Fatigue (10)
- Sweats and night sweats (10)
- Fever (8)
- Cough (7)
- Unexplained weight loss (3)
- Loss of appetite (1)
- Shortness of breath (1)

The participants named signs of TB, with only seven people pointing out cough. The reason for this could be that half of the respondents never felt sick before TB was diagnosed; they could not be properly informed by medical staff; TB symptoms in people living with HIV could be hidden and cough could be absent.

Six participants don’t know how they got TB. Three got TB in institutions of confinement and the rest got it by contact with sick people.

The majority of the informants (9 people) believe that TB is curable by:

- Taking proper treatment, following doctors’ instructions (7)
- Eating healthy (5)
- Folk medicine in combination with conventional treatment (2)
- Only hospitalization (1)

Two participants deem that treatment can suspend TB but not cure it, with one of them believing TB is incurable and the other one does not really know. The patient who thinks that TB is incurable has struggled with the disease since he was 10 years of age and now is on re-treatment. This long history of treatment might explain his opinion. In general, participants lean toward the idea of TB curability.

Six (55%) felt sick before they went to the doctor. The symptoms were fatigue, weight loss, and coughing. Three never felt sick and just incidentally found out that they have TB: one during a checkup at the AIDS center; another discovered it during confinement. He also mentioned that he didn't feel sick because of taking ARV drugs.

Answering the question of how the disease was diagnosed, the informants indicated fluorography (11), with a sputum test (8) and other tests (6) (e.g. blood and urine test), and one mentioned the Mantoux test. After they were diagnosed, six started the treatment immediately or within one week, two - after two months (one explained it was because of the absence of the doctor who indeed diagnosed them with TB), two in 6-12 months (one of them was in a prison). The majority (5) were diagnosed in a TB center, four people in prison, and two in an outpatient department in primary health care.

All treatment was received for free through hospitalization at a government facility for three people (27%), and the rest were not hospitalized, including two who were denied treatment due to lack of space, two were hospitalized in prison, one didn't like the conditions in the hospital and rejected the second hospitalization. In total, six people were hospitalized (one person twice) for a period of from two months up to two years and were satisfied with it because of meals (60%), treatment, receiving information about TB, because "it's better than prison" and because "It's necessary to take treatment". Five participants out of the total said that the medical staff insisted they complete their treatment. Answering the question "Did the staff in the health care facilities where you received treatment emphasize the need to complete treatment to cure TB?", Four people said that they themselves were eager to receive treatment in order to get cured.

In general, half of the respondents (5) are satisfied with the information and support given by the health staff. The following kind of information was received: consultations, talks and brochures.

Four people who were not satisfied with all the services from the health staff were not hospitalized; one of them visited a doctor just three times. One person who was already hospitalized and refused for the second time said that information and support from the health staff used to be better.

In general, the patients are mostly satisfied with conditions of hospitalizations, including meals and information provided by the medical staff.

Why is it important to continue and finish the TB treatment until the end? (Number of participants)

- To get cured because it's a deadly disease (2)
- Because one can infect others (2)
- TB can get worse, transform and reoccur (3)

This information was provided by health staff (e.g. tuberculosis specialist, nurse, head doctor, physician) NGO and one person knew it himself.

Why is it important to take the TB treatment regularly? The answers were mostly general and not specific (e.g. "Yes, I know it's important to finish the treatment" or "Annual checks are necessary"). Among the rest of the responses the following reasons were provided:

- Resistance to the treatment (50%)
- Relapse (40%)
- Bacterium become more active (10%)

Given the general nature of the majority of responses, it seems clear that the respondents are not fully aware of the reasons for regular and continuous TB treatment adherence.

Only 27% (3 persons) missed doses during their treatment because no one controlled them (in prison); they were too busy (e.g. with small baby); and one couldn't afford usage of public transport to get to the health care facility. The majority were motivated to take treatment by medical staff (82%) including self-control and self-motivation (22%) and relatives (11%). People took a serious and responsible approach to their treatment, resulting in regularly taken doses, which is usually not easy for patients.

Seven participants told everyone that they had TB, four only disclosed their TB disease to their family and relatives. Seven confronted "normal" and understanding reactions to their status, two experienced negative reactions, including rumors by neighbors and lack of understanding from a mother with later sympathy and support (1). Only two participants reported problems they faced because of their TB: with neighbors (as mentioned before) and one who had to quit her job. Two didn't tell their colleagues that they had TB, thus didn't have problems at their workplaces. Only one reported being discriminated against by his neighbors, who didn't let peers to interact with him (it was in childhood many years ago). Hereby, TB patients are barely discriminated at workplaces mostly because they don't tell their colleagues. Family generally support patients and treats them with understanding.

Three declared that their family suffered because they had TB, and suggested providing families with information about TB and with psychological support.

One person is afraid that her HIV status will be revealed. One participant mentioned that his HIV-status causes complications and transformation of TB. For the rest of the participants, the HIV status didn't have any influence on TB diagnosis and treatment.

The respondents received social and psychological support mostly from NGOs "Doveriye Plus" (64%), "Shapagat" (27%) including food supply, one person barely got

support from his family and community and none from any NGOs.

Obstacles experienced in accessing heath services and getting TB treatment

Three people admitted that they were facing financial problems during their treatment mostly because of public transportation costs even though the treatment was free of charge. There was only one suggestion for home delivery of all anti-TB drugs, so they would not have to spend money and time to travel to and from the medical facility.

Four respondents spend 20 minutes by bus to get from the place where they live to the health facility; for another four people, it takes 30-60 minutes by bus. One person had all medications delivered at home; one received the full course of treatment in prison.

Overall, only two respondents were not happy with the treatment and care. The changes suggested were the following:

- Psychological support and a psychologist available for counseling family members, and in institutions of confinement for patients.
- Diversify leisure time in hospitals, provide magazines, newspapers.
- More information about TB for patients and their relatives.

5. Results

5.1. Results from the Focus Group Discussions

In conclusion we would like to bring together results among all four MARP groups. The most TB-informed group can be considered PLHIV. More or less, the participants are aware of the most important signs of TB, excluding the MSM group. As not all MARPS know about the intensive and continuous phases of TB treatment, probably information about the stages should be included in future in the order to avoid misunderstanding.

Knowledge about TB among all groups of MARPs is generally poor and sometimes inadequate especially concerning means of transmission and signs of TB, which are crucial in terms of identification, prevention and treatment. General but limited awareness of TB transmission shows that all groups require more information on this topic.

Care seeking behavior among the respondents can be assessed as satisfactory. Probably, additional information on where to go in case of TB is required among the SW group and MSM.

Not all MARPs know that TB treatment is free, thus some of them believed that financial concerns most probably can prevent these people from seeking care and treatment. Therefore, the message that TB treatment is free should be strengthened during outreach activities.

The most intolerant to TB patients seems to be MSM group. Together with SW, they are

the least knowledgeable about TB (transmission, signs, etc.). Concerning barriers, MSM and IDU have some internal barriers (motivation, emotions, feelings, such as laziness, fear) toward care seeking and treatment in case they had TB. PLHIV identified several external barriers (negligence of medical staff, their rudeness, and family circumstances) toward the care seeking and treatment in case they found out they had TB.

Printed materials are the most needed among all four groups. Video materials, especially on TV, would also be very interesting to these groups.

This research might also assist feature programs for focus groups and in-depth interview development in order to fulfill obvious gaps identified, including questions such as, why do you feel fear when seeking help or treatment?

5.2. Results from the In-depth interviews

To summarize the results described above, we would say that this group of people, with either TB or TB/HIV:

- in general, know the symptoms of TB,
- the majority of respondents believe that TB is curable
- all respondents know that TB treatment is free of charge thus they have received it
- the majority of the group realizes that it is important to continue and finish TB treatment and are aware of the reasons for regular and continuous TB treatment
- only one-third of respondents missed any doses during their treatment
- respondents didn't mention confrontation, real discrimination or stigmatization
- support was mostly provided by families, NGOs and medical staff

At the same time,

- more than half of the respondents do not know the means of TB infection
- most respondents think that fluorography is the main way to identify TB
- in spite of treatment being carried out more or less effectively and on time, only half of the participants began treatment within one week after diagnosis
- only half of the respondents are satisfied with the information and support given by health staff

Therefore, these topics need to be emphasized while working with these MARPs.

6. Conclusions

In conclusion, all of the FGDs and In-depth interviews identified a low level of accurate knowledge about TB transmission, services and that TB is curable. This lack of knowledge, and assumed or actual associated costs for care, can be significant barriers to seeking and receiving treatment for TB among all of the MARP groups. Increasing the availability of information and reaching out to members of these groups can contribute to earlier care-seeking and a demand for accurate and timely treatment.

Annex 1.

Focus group Discussion Guide

A. Objectives of Focus Group Interview

1. What are the TB related knowledge, attitudes, practice and behaviors among the target group?
2. What are the obstacles experienced by them to accessing heath services and getting TB treatment?

B. Target Group(s)

PLHIV, SW, IDU, MSM
and migrants (year 2).

C. Introduction:

- Thank participants for coming.
- Explain what a focus group discussion is in general and explain the objective of this specific focus group.
- Explain that notes will be taken.
- Assure them that their names will not appear in any report. Their answers are confidential.
- Ask permission for use of the tape recorder before conducting FGDs and in-depth interviews.

D. Discussion Questions:

1. Knowledge about TB:

1. What do you know about TB?
    a) What are the most important signs of TB?
    b) How TB is transmitted?
    c) Is TB curable?
    d) How long is TB treatment?

2. Care seeking behavior:

2. If somebody has TB symptoms, where should he/she go for help/advice?
    a. Can he/she go to a PHC facility or TB center?

3. Barriers for seeking care and getting treatment:

3. I would like to find out - if you had TB, what would prevent you from seeking care and getting TB treatment?

a. If you wanted to seek care and treatment, would you be able to do so by yourself? Is anyone else connected to your seeking care and treatment?
b. How would you feel about going to seek care and treatment?

4. Motivators for care seeking and getting TB treatment:

4. If you had TB, what would motivate you to seek care and get treatment?

    a. Is seeking care and treatment important for you?
    b. What kind of support would be helpful for you to seek treatment? Financial, family, friends, some kind of incentive?

5. Needs for additional information on TB:

5. Who can get TB? What kind of people?
    a. Why do people get TB?
    b. What do you think about TB patients?
    c. Do you know somebody with TB?
    d. Would you be friends with someone who has TB?

6. Needs for additional information on TB:

6. What additional information about TB would you like to receive?
    a. In what language?
    b. In what form would you like to receive this information?

E. Conclusions and Closure

1. Summarize the interview

2. The facilitator can review the questions, and read a few responses. The participants should be given an opportunity to correct something that was said, or add a comment.

3. Thank the participants and reassure them that their remarks are strictly confidential, that the information they have provided will be used to develop health messages for IEC materials.

Distribute booklet and a small gift to all the participants.

Annex 2

In-depth Interview - TB Patients among PLHIV in Tajikistan, Interview Guide

(Adapted from protocol developed by Project Hope for a Qualitative study on TB among Migrants from Uzbekistan)

General Information

1. Date:
2. Time start interview: Time end interview:
3. Place:
4. Name of interviewer:
6. Current status:
7. Gender:
9. Age:
10. Region:
11. Marital status:
12. Education:
13. Profession:
14. Family situation:

Informed consent is obtained*: _____ (signature of facilitator)

* The facilitator has to explain the objectives of the interview to the patient and ask for his/her consent/agreement to participate in the interview. If the person agrees to participate voluntary in the interview, the facilitator can put his/her signature in this space.

2. Questions

(Following is a list of open-ended questions to lead the interview. Each question should be asked but the order and wording may be changed. A follow-up question for probing and for clarification should be added. It may happen that some questions will be already answered by the participant before (when answering another question). If this is the case you don't have to ask the question again (because the answer was already given before). Take notes during the interview. Write the questions as you asked them (your wording,

order, probing follow-up questions, etc.) and the response of the participant. The interview can be also recorded by a tape recorder. Ask consent of the participant for this.

1. How long ago were you diagnosed with TB?_____

2. Are you still on treatment for TB? If not, how long ago did you finish your treatment?_____

3. How long did you take TB treatment? Are you cured now? Do you still have to go to a health facility for follow-up checking and/or treatment? If yes, explain; how often do you have to go, what kind of examinations are done? Do you still have to take some kind of drugs/treatment because you previously had TB? If yes, what kind of treatment/drugs?_____

_____

_____

4. What are the most important signs of TB?_____

5. How do you get TB?_____

6. Is TB curable? If so, how?_____

7. When you became sick, where did you go first for help/advice? How long was this after you started to feel sick?_____

8. Where (in which facility) and who told you that you had TB? How long was this after you started to feel sick?_____

9. Do you know how they diagnose TB? If yes, explain how._____

_____

10. How long did it take after you knew you had TB to start the actual TB treatment? (If there is a delay of more than 1 week, ask the reason for this?)_____

_____

11. What kind of treatment did you receive? Where (from private pharmacy, hospitalized in government health facility, at the PHC, first hospitalized later at another health facility, all hospitalized, etc) did you receive this treatment?

_____

_____

12. If the person was hospitalized ask: How long have you been you hospitalized? Was it OK for you to be hospitalized? If yes, explain. If no, would you prefer to receive the treatment in a different way? If so, in which way? _____

_____

_____

13. Did the staff in the health care facilities where you received treatment emphasize the need to complete treatment to cure TB?_____

_____

14. Are you satisfied with the information the health staff gave you about TB and about the treatment for TB? What kind of information about TB did you receive from the health staff (i.e. any discussions, demonstrations, brochures, DVD etc)? Are you satisfied with the support of the health staff?_____

_____

_____

15. Do you know why it is important to continue and finish the TB treatment until the end? If so, explain why? Who explained this to you?_____

_____

16. Do you know why it is important to take the TB treatment regularly? If so, explain why? Who explained you this?_____

_____

_____

17. Have you ever missed doses of your TB treatment? If so, what was the reason for this? Who motivated you to continue treatment? Who was observing you when you take your medicines?_____

_____

_____

18. Did you tell people (family, friend, community members, colleagues, etc.) you had TB? If yes, who did you tell it and what was their reaction?_____

_____

19. Do or did you have problems in your family, community, at your workplace, because people know that you had TB? What kind of problems? Are or were you discriminated against because people know you had TB? If yes, explain. Do or did you receive support from people who know you had TB? Did you receive any social support (e.g. from community, authorities, NGO's)? If yes, explain._____

_____

_____

20. Did you have enough financial means to get the necessary help and treatment for your disease? What are the services you have/had to pay for as TB patient (e.g. X-ray, hospitalization, medication, transport, etc.) and could you afford this? If not, do you have suggestions how the financial burden can be reduced? Did you have to borrow money to for the TB treatment?_____

_____

_____

21. How long did it take to go from the place where you live to the place where you received your treatment? (If the place where the person received his treatment is not mentioned yet, ask the name, kind and location of this place) How did you go to the place of your treatment? Could you afford (financially and geographically) to regularly go to this facility for treatment? If not, do you have suggestions to solve this issue?

_____

_____

22. If the patient has a family, ask: Does and/or did your family suffer from the fact that you had TB? Do you have suggestions how to improve the situation for your family?_____

_____

23. Did the fact that you have an HIV status in any way influence your TB diagnosis and treatment? (Were you hesitant to seek care, were you ever denied treatment, were you afraid of having your status revealed?)_____

_____

_____

24. Overall, were you happy with the TB treatment and care you received (including 2 months of hospitalization)? If not, which changes would you suggest?_____

_____

_____

These are a lot of questions. The interviewers should try to turn these into a flowing conversation about the health seeking path that the participant has gone through, let the participant tell his/her story without going through the list of questions one by one.

Thank you very much for your time and your help!