Evaluation of factors affecting the behavior of target groups in health care-seeking and tuberculosis treatment

Social and Behavior Change Formative Research Final Report

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USAID Cure Tuberculosis Project
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Acronyms

- DND: doer/non-doer
- DOT: directly-observed treatment
- DR-TB: drug-resistant tuberculosis
- FGD: focus group discussion
- HCW: health care worker
- LTFU: lost to follow-up
- MDR-TB: multi-drug resistant tuberculosis
- NTP: National Tuberculosis Program
- PLHIV: people living with HIV
- SBC: social and behavior change
- TB: tuberculosis
- VHC: village health committee
Executive Summary

The five-year (2019–2024) USAID Cure Tuberculosis Project is assisting the Government of the Kyrgyz Republic to diagnose, treat, and cure people with drug-resistant tuberculosis (DR-TB). Kyrgyzstan has one of the highest rates of DR-TB in the world, and the Project focuses on reaching those most vulnerable to TB. Based on a situation analysis of risk groups for TB and barriers to testing and treatment in Kyrgyzstan (Annex 1), the Cure Tuberculosis Project designed a formative research study to inform the development of a project social and behavior change (SBC) strategy. The study had the following objectives:

1) understand the perspectives of persons with TB and their household members on seeking diagnosis, starting and completing treatment;
2) explore the factors that underlie the widespread stigma of TB patients;
3) learn about possible support systems and channels of communication for reaching high-risk groups including former prisoners, migrants, people who misuse substances, people living with HIV, and people who are homeless.

The research study was conducted February–March 2020 in Naryn, Chui, and Jalal-Abad Oblasts and Bishkek city. The study is a qualitative research study consisting of focus group discussions, semi-structured interviews, and structured interviews called doer/non-doer questionnaires (tools in Annex 4). Data were analyzed using standard qualitative analysis techniques. For the doer/non-doer interviews, responses were coded, tabulated, and ranked by frequency to establish enabling factors and barriers to specific behaviors.

The study identified many differences between the original hypotheses established for each target group based on the situation analysis and the findings of the study for each group, including gender aspects, health care situation for migrants, specific deterrents to seeking and completing treatment, and the role of health workers and family support in treatment.

The study results revealed the following enabling factors and barriers for seeking testing and completing treatment. For the behavior of starting treatment, it was impossible to recruit sufficient non-doers (people diagnosed with TB who did not start treatment) to enable a robust analysis, but barriers and enablers were similar to those found for testing. This behavior was dropped from the SBC strategy after additional data collection indicated that the behavior may not be as problematic as hypothesized: health workers do a good job of encouraging patients to start treatment, and patients are interested in getting well.

Study scope:
- 25 focus group discussions with men and women from the general population, external migrants and their families, internal migrants, and health care workers
- 277 doer/non-doer interviews on testing, starting and completing treatment, and stigma
- 23 semi-structured interviews with high-risk groups and staff working with high-risk groups
# Main Findings: Enabling Factors and Barriers

<table>
<thead>
<tr>
<th>Enabling factors for seeking testing</th>
<th>Barriers to seeking testing</th>
</tr>
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<tbody>
<tr>
<td>1. Self-motivation to know one’s TB status</td>
<td>1. Lack of time</td>
</tr>
<tr>
<td>2. Concern about infecting family members</td>
<td>2. Cost of diagnostic tests</td>
</tr>
<tr>
<td>3. Knowledge that treatment is effective</td>
<td>3. Lack of transportation</td>
</tr>
<tr>
<td>4. Having someone to take over household responsibilities</td>
<td>4. Concern about stigma</td>
</tr>
<tr>
<td>5. Access to free testing</td>
<td></td>
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<tr>
<td>6. Receiving rapid results</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Enabling factors for completing treatment</th>
<th>Barriers to completing treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Desire to be cured</td>
<td>1. Drug adverse reactions</td>
</tr>
<tr>
<td>2. Concern about infecting others</td>
<td>2. Difficulties with drug intake</td>
</tr>
<tr>
<td>3. Feeling better after starting treatment</td>
<td>3. Family issues</td>
</tr>
<tr>
<td>4. Advice and support from health workers or NGO staff</td>
<td>4. Alcohol dependence</td>
</tr>
<tr>
<td>5. Convenience of the treatment regimen</td>
<td>5. Co-existing illnesses</td>
</tr>
<tr>
<td>6. Receiving material incentives or good hospital care</td>
<td>6. Inconvenience of daily travel to health facilities</td>
</tr>
<tr>
<td>7. Lack of residence registration</td>
<td>8. Long duration of treatment</td>
</tr>
</tbody>
</table>

The main sources of support mentioned by participants in helping them to complete treatment were family and health care workers, with some also receiving support from NGO workers.

Focus group discussions and interviews revealed a wealth of misinformation about TB, including misconceptions about:

- causes (cold/damp conditions, deterioration of other respiratory illnesses)
- transmission (through dishes, food, clothes)
- inheritability (genetic, affecting ability to have healthy children)
- treatment and curability (ineffective drugs, incurable, chronic TB, folk medicine)
- many stereotypes about the types of people who contract TB, with mention of prisoners, smokers, people who misuse alcohol, poor people, and those who have poor hygiene.

Stigma was revealed to be widespread in the study, fueled by misinformation and a fear of contagion, and there were regional differences in expressions of stigma. Some patients indicated experiencing stigma from health workers who are non-TB specialists. A causal analysis of stigma (Figure 1 on page 27) portrays how community-level factors and patient-level factors lead to stigma via a fear of contagion and concern about social labelling. The most significant social consequences of stigma include abandonment by family, loss of marriageability, self-isolation and self-stigma.

Four types of stigma identified:

- Public stigma
- Perceived stigma
- Self-stigma among TB patients
- Secondary stigma towards health workers who treat TB patients
The formative research findings were used to develop the project SBC strategy with tailored messages and channels of communication for each target group; defining actions to reduce stigma; and incorporating specific recommendations on disseminating information to dispel myths and misconceptions on TB and to raise awareness that TB is curable, treatment is free, most people are no longer contagious after the start of treatment, and it is important to complete the full course of treatment. Given the crucial role of health workers in treatment support, training on regular counseling of TB patients and development of interpersonal communication skills for health workers and NGO staff are critical.

**Recommendations for improving the enabling environment for TB care and treatment that require national consensus and coordination:**

- All partners should work together to scale up community-based directly observed treatment (DOT), the case management approach, and incentive payment system for outpatient treatment to provide better patient-centered care.
- Efforts should be made to improve drug regimens for patient convenience, and advocate for patient incentives, including through local government financing.
- All medical staff, including non-TB specialists, should be trained on TB and stigma against TB patients.
- Special attention should be paid to the issue of alcohol dependence, with alternative forms of DOT and related services for affected groups.
- Treatment access should be improved for high-risk groups by advocating for simplification of the procedures for accessing treatment currently based on residence registration.
Introduction

Kyrgyzstan is among the 30 countries with the highest burden of drug-resistant tuberculosis (TB) in the world. Kyrgyzstan registers over 6,000 new cases of TB each year, more than 1,400 of which are drug-resistant. Drug-resistant TB is very difficult to diagnose and treat, and requires a course of treatment that can last up to two years, accompanied by many drug side effects. Due to treatment difficulties, adherence is a significant challenge for many patients and treatment success rates for drug-resistant TB are typically low. While drug-sensitive TB has a treatment success rate of 82%, the treatment success rate is only 53% for multi-drug resistant TB (MDR-TB) and as low as 15% for extensively drug-resistant TB.\(^1\) Timely and accurate diagnosis of drug-resistant TB is key to starting patients on an appropriate treatment regimen, and adherence during the long course of treatment is critical to achieving treatment completion and cure from tuberculosis.

The five-year (July 2019-July 2024) USAID Cure Tuberculosis Project is assisting the Government of the Kyrgyz Republic to diagnose, treat, and cure people with drug-resistant TB. The Project is implemented by JSI Research & Training Institute, Inc. (JSI) in partnership with University Research Co., LLC. Key project partners include the Ministry of Health, National TB Program (NTP), Republican Health Promotion Center, and the Mandatory Health Insurance Fund. The implementing consortium also includes the following sub-grantees: National Red Crescent Society, Association of Village Health Committees, TB People in Kyrgyzstan Public Foundation, and the Kyrgyz Republic Hospital Association. The project began implementation in Jalal-Abad, Chui, Talas, and Naryn Oblasts and will expand to Batken, Osh City, Bishkek City, and Issyk-Kul Oblasts in subsequent years.

The project’s overall purpose is to reduce the burden of DR-TB in the Kyrgyz Republic. The project will do this through the following sub-goals:

1. Increased DR-TB case detection
2. More DR-TB patients cured
3. Prevention of DR-TB infections
4. Improved enabling environment for TB treatment

People at risk of contracting tuberculosis are often hard-to-reach, which can make it difficult for them to access health services. The Cure Tuberculosis Project works closely with the Government of the Kyrgyz Republic to improve the quality and accessibility of TB services, even for people who have difficulties accessing care.

People considered at high risk of contracting TB include close contacts of people with TB; people living with HIV (PLHIV); people with other illnesses; people who live in compact and crowded settings, including current and former prisoners; people with no fixed abode; and people subject to the influence of alcohol and drugs, including people who inject drugs (PWID). Labor migrants who leave the country to earn money abroad are also at high risk due to crowded living situations and unfavorable work conditions, as well as limited access to medical care. Other compounding social factors such as poverty, unemployment, and malnutrition contribute to TB.\(^2,3\)
Based on an initial situation analysis, the project team and partner organizations’ staff have identified gaps in the information needed to plan and implement activities to achieve the goal and sub-goals, specifically a better understanding of the perceptions of persons with TB, their families, and communities that support or impede detection and treatment of DR-TB. To fill those information gaps, the Cure Tuberculosis Project proposed a formative research study to learn more about the target populations.

Objectives of the study

1. Understand the perspectives of persons with TB and their household members on seeking diagnosis, starting and completing treatment.
2. Explore the factors that underlie the widespread stigma of people who have TB.
3. Learn about possible support systems and channels of communication for reaching high-risk groups including former prisoners, migrants, people who misuse substances, PLHIV, and people who are homeless.

The results of the study were used to inform the social and behavior change (SBC) strategy, including selection of key messages, activities, target groups, and channels of communication. In addition, the findings help determine methods to be used by health workers, volunteers, and village health committees (VHCs) to inform, identify, and track persons needing diagnosis and treatment.

Background on TB and key risk groups

Overall, TB notification and mortality in Kyrgyzstan have been on a steady decline since 2001. However, MDR-TB notification has been rising significantly, from 835 cases in 2009 to a record of 1,685 laboratory-confirmed MDR/rifampicin-resistant TB cases in 2018. The estimated proportion of MDR/rifampicin-resistant TB is 29% among new cases and 68% among relapse cases.4

A total of 6,338 new and relapse cases were notified in 2018. Men represent 57% of all TB notifications, while women and children represent 39% and 4% respectively. The majority of new and relapse cases (53%) occur among the 18–44 age group. However, new cases are more prevalent in younger generations, whereas relapse cases occur more in the older age groups.5 HIV testing among TB patients is almost universal. Almost 3% of cases are TB/HIV co-infected, and 71% of co-infected cases are receiving anti-retroviral treatment.6

Of all TB cases notified in 2018, the proportion that were DR-TB was as high as 27% in Bishkek City, 25% in Chui Oblast, 23% in Jalal-Abad Oblast, and 20% in Naryn Oblast. After Osh City (33%), the highest proportions of lost to follow-up (LTFU) DR-TB cases were in Bishkek City (30%), Naryn Oblast (27%), Chui Oblast (26%), and Jalal-Abad Oblast (23%).7

Among all TB cases notified in 2018, the following risk factors were recorded: 49% of cases were among people who are unemployed; 15% among people with co-morbidities; 11% among people who smoke; 8% among internal migrants; 7% among external migrants; 5% among people who are dependent on alcohol; 4% among TB contacts; 4% among current and former prisoners; 3% among PLHIV; 2% among people who are homeless; and 1%
among people who use drugs.\textsuperscript{8} However, official statistics on TB in high-risk groups may be underestimated due to difficulties in registration, a lack of systematic collection of information on risk factors, and the reluctance of patients to provide information about their belonging to a particular stigmatized risk group.

A more detailed situation analysis of TB among key risk groups based on existing literature, including factors affecting diagnosis and treatment, is presented in Annex 1.

Methodology

Ethical approval
The protocol for the study was approved by JSI’s institutional review board (IRB) on January 16, 2020 and by the Ethics Committee of the Ministry of Health of Kyrgyzstan on February 4, 2020.

Type of study and duration
The study was qualitative, using focus groups, semi-structured interviews, and a brief structured interview of specific individuals (doer/non-doer questionnaires) to collect the desired information (questionnaires attached in Annex 4). The study took place over a period of one month (February–March 2020) in Naryn, Chui, and Jalal-Abad Oblasts, with some specific information collected from defined groups in Bishkek city.

Geographical coverage
Naryn, Chui, and Jalal-Abad Oblasts were selected for this study because they are pilot areas of the Cure Tuberculosis Project, and could capture social, cultural, ethnic and livelihood differences between the northern (Naryn, Chui) and southern (Jalal-Abad) regions of the country. In Naryn, the population density is much lower (6.4 people per km\textsuperscript{2}), and there are large distances between cities and villages (this is the largest oblast by area), which makes it harder to access health services. In Jalal-Abad, the population density is much higher: 36.8 people per km\textsuperscript{2} (representing 19\% of the total population of the country). In Chui, the population density is 47.5 people per km\textsuperscript{2}. The average population density in Kyrgyzstan is 32.6 people per km\textsuperscript{2}.

The ethnic composition of the population of the country's regions also varies. According to the latest available census data (2009), in Naryn the population is mono-ethnic: 99\% of the total population of the region are Kyrgyz. In Jalal-Abad, two ethnic groups prevail: Kyrgyz (72\%) and Uzbek (25\%). In Chui, the ethnic composition of the population is the most diverse: Kyrgyz (59\%); Russian (20\%); the rest of the population comprises Dungans, Uighurs, Uzbeks, Ukrainians, Turks, and representatives of other ethnic groups.

Priority groups included in the study
Drug-resistant TB is widespread in Kyrgyzstan. According to NTP statistics presented earlier, cases of TB and DR-TB occur both among high-risk groups and the general population. For this reason, the study targeted both high-risk groups as well as the general population in order to form a comprehensive understanding of the situation to develop targeted messages by group. The targeted population groups are shown below in Table 1.
### Table 1. Priority Groups Included and Justification

<table>
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<tr>
<th>Priority group</th>
<th>Reason for inclusion</th>
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<tr>
<td>Men from general population</td>
<td>Men may seek diagnosis earlier than women and show less concern about stigma. It is important to understand why men and women differ.</td>
</tr>
<tr>
<td>Women from general population</td>
<td>Women may not seek diagnosis or treatment at the same rate as men and a large majority have expressed concern about stigma.</td>
</tr>
<tr>
<td>External migrants and their families</td>
<td>Migrants are at risk for DR-TB as many do not seek or continue treatment when living outside the country. It is important to learn about the barriers they face when abroad and how they prioritize their health relative to earning money.</td>
</tr>
<tr>
<td>Internal migrants</td>
<td>TB rates are high among populations in the new settlements. The project wants to understand the barriers to diagnosis and treatment among this group.</td>
</tr>
<tr>
<td>People who are homeless</td>
<td>Compliance with TB treatment is very low among this group. We need to learn how health workers might remain in contact with them to provide treatment. Much of this information can be learned by interviewing workers at homeless shelters.</td>
</tr>
<tr>
<td>People who misuse substances and PLHIV</td>
<td>People in these groups have a low rate of treatment compliance. It is necessary to learn about their networks of support and how health workers can find and help them to continue their treatment.</td>
</tr>
<tr>
<td>Former prisoners</td>
<td>Persons who are diagnosed with TB and start treatment while in prison have a very high risk of stopping treatment when they are released. It is important to learn how they can be reached after they are released and how to persuade them to seek these services.</td>
</tr>
<tr>
<td>Health workers</td>
<td>Health workers face challenges in working with TB patients and some express concerns about working with them, which indicates that they may show stigma toward TB patients. Learning about their attitude and concerns will help formulate plans to improve quality of care.</td>
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#### Sampling

The aim of qualitative research is not to acquire a representative sample but to produce a deeper understanding of a particular situation. Wider implications come not from the breadth or diversity of the sample, but from the depth of understanding. The sample thus included groups of men or women in the same situations or communities to generate hypotheses for similar groups, taking into account gender dynamics and regional differences.

Sampling for this study was purposive, allowing for inclusion of both urban and rural populations in each oblast and the specific priority groups listed in Table 1. Site selection was influenced by accessibility in winter. Health facility, Red Crescent, and VHC staff helped select villages and recruit participants using convenience sampling. Participants for
individual interviews on the rubrics of TB testing, starting, and completing treatment were identified with health facility staff in accordance with TB registers (TB 02).

For the special populations of high-risk groups, the study was implemented through partners Red Crescent and TB People, who had existing relationships with these groups and helped conduct interviews. Particular care was taken to safeguard the identity of study participants.

**Data collection tools**
The data collection tools included guides for focus group discussions (FGDs) with specific groups of interest, and semi-structured and structured interview tools asking about individual perceptions related to stigma, seeking diagnosis, starting treatment, and completing treatment. A total of 15 questionnaires were developed and pre-tested by the project team and consultants (see tools in Annex 4).

**Focus group discussions**
The FGD guides for the general population of men and women explored knowledge of TB as a disease, understanding of transmission and treatment options, attitudes reflecting stigma, and sources of information or preferred learning. The FGD guide for internal migrants explored similar themes as well as challenges to accessing treatment. The FGD guides for external migrants aimed to understand life priorities (work, health, family, money), challenges to obtaining health services, and communication with family at home.

**Doer/non-doer interviews**
The doer/non-doer (DND) method uses a seven-question tool developed originally in the field of HIV, which enables researchers to quickly identify differences between those who have carried out a recommended health practice (so-called “doers”) and those who have not (“non-doers”). The tool is used to elicit the individual’s awareness of the recommended practice and its benefits, perceived disadvantages, perceived barriers, enabling factors, and individuals who do or do not support the person in adopting the recommended behavior. Detailed guidance is available on using this methodology for a wide variety of health behaviors.

**Tuberculosis testing and treatment**
In this research study, the three behaviors of interest for TB were seeking testing in case of symptoms, starting treatment after TB diagnosis, and completing treatment. The doer/non-doer questionnaires were therefore administered to:

- People with symptoms of TB (cough, etc.) who sought testing versus those who did not.
- People with diagnosed TB who started treatment versus those who did not.
- People on treatment for TB who completed treatment versus those who did not.

A set of specific verbal screening questions was used at the beginning of each interview to determine the phase of testing or treatment a respondent was in to correctly assign the respondent into the testing, start treatment, or complete treatment categories. These verbal questions were also used to sketch a brief treatment history of the patient with
questions as to whether the person had regular (drug-sensitive) TB or drug-resistant TB. If the patient did not know, specific clues (e.g., length of treatment, number of pills, presence of injections, location/duration of hospitalization) were later used from the narrative to determine this. The screening questions, as well as the specific inclusion and exclusion criteria for these doer/non-doer interviews are included in Annex 5.

Stigma
In addition, DND questionnaires on the topic of stigma were administered to women. In this case, the behavior of interest was telling others about a TB diagnosis in the family (doers) versus hiding a TB diagnosis from anyone outside the immediate family because of shame or stigma (non-doers). Inclusion criteria included having a family member with TB.

Semi-structured interviews
The semi-structured interviews with homeless shelter staff, NGO staff, and health care workers in prisons elicited information about high-risk groups and challenges working with them. The semi-structured interviews with health care workers who care for TB patients explored their perceptions of patients and their challenges, caseloads for TB versus other responsibilities, and stigma. Interviews with high-risk groups, including people who are homeless, people who misuse substances and PLHIV focused on their general living conditions, registration status, access to health care and access to information.

As an important component of the larger study, stigma was explored through multiple methods. The level and types of stigma were assessed among the general population (through FGDs); among women who are family members of TB patients (through stigma DND questionnaires); people with symptoms of TB and TB patients (through DNDs); and health care workers (through FGDs and semi-structured interviews). The DND questionnaires for people with presumptive or diagnosed TB aimed to reveal how much of a barrier stigma may be to seeking diagnosis or completing treatment.

Data collection process
All the data collection tools and guides were tested in the field prior to official start of the study, with amendments made accordingly. Before the start of each interview or focus group, a statement of informed consent was read to the participants, explaining the purpose of the study and seeking their signature as consent to participate. Copies of these informed consent forms are presented in Annex 3 and 4. All research team members received training on data collection methods and confidentiality and ethical issues prior to the start of fieldwork.

Data were collected manually on paper forms, mainly in Kyrgyz, and transcribed and translated into Russian and English. Part of the data was collected in Russian (especially interviews with health care workers). In areas of Jalal-Abad Oblast with a predominantly Uzbek population, data were collected in Uzbek, followed by translation into Russian and English. Focus group discussions and semi-structured interviews were recorded on mobile phones, with the consent of participants, as back-up to the written notes. For qualitative data analysis, all the records, notes, and the audio recordings of the FGDs were transcribed in written form.
Scope of the formative research
The study covered Naryn, Chuy, and Jalal-Abad Oblas and Bishkek and Jalal-Abad cities. In total, 547 people participated in the study. Below is a brief synopsis of study design; more detailed information on the scope of the formative research can be found in Annex 2.

<table>
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<th>Scope of Formative Research</th>
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<tr>
<td>• 3 oblasts – Naryn, Chui, Jalal-Abad + high-risk groups in Bishkek</td>
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<tr>
<td>• 25 focus groups (247 participants) with:</td>
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<tr>
<td>o General population: men (3); women (9); youth (2)</td>
</tr>
<tr>
<td>o External migrants (4); internal migrants (2); families of migrants (2)</td>
</tr>
<tr>
<td>o Health care workers (3)</td>
</tr>
<tr>
<td>• 277 DND interviews (188 doers and 89 non-doers) on:</td>
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<tr>
<td>o Testing</td>
</tr>
<tr>
<td>o Starting treatment</td>
</tr>
<tr>
<td>o Completing treatment</td>
</tr>
<tr>
<td>o Stigma</td>
</tr>
<tr>
<td>• 23 semi-structured interviews with:</td>
</tr>
<tr>
<td>o High-risk groups (12)</td>
</tr>
<tr>
<td>o Staff working with high-risk groups: homeless shelter staff (6); prison health care workers (3); NGO staff working with former prisoners (2)</td>
</tr>
</tbody>
</table>

Data analysis
Following review of transcriptions of FGDs and semi-structured interviews, data were coded thematically using standard qualitative analysis techniques, and analyzed using content analysis and analytic induction.

Doer/non-doer interviews analysis required first assigning each respondent into the appropriate category during data collection (testing, start/complete treatment, or stigma), and then classifying each respondent as a doer or non-doer for the desired behavior based on his/her responses. Analysis is semi-quantitative to compare responses of doers to those of non-doers. Responses for each question are categorized and tabulated separately for doers and non-doers.

Responses to each of the seven questions in the DND questionnaire were first analyzed to group similar responses into codes. Responses by code for each question were then tabulated and tallied to establish simple frequencies of each response. Then the relative importance of responses was calculated separately for doers and non-doers as a percentage (of people who mentioned the response) of the total number of doers and non-doers, respectively. The most common responses were then ranked in order of importance by each category of respondent. Tabulation was initially done by oblast for the different topics, and when no major differences were found between oblasts, the responses were compiled across oblasts.
Results

Factors affecting seeking diagnosis, starting treatment, and completing treatment
This study used the DND tool specifically validated to identify the factors that either positively or negatively affect the person’s care-seeking and compliance behaviors. The tool elicits this information from the perspective of the client or patient, which is critical for developing person-centered strategies to improve these behaviors. Below is a summary of enabling factors and barriers to testing, starting treatment, and completing treatment.

Enabling factors and barriers to seeking testing

The following enabling factors were identified for seeking testing. They are listed in order from most frequently mentioned to the least. Each factor represents a category of related responses from the interviews.

1. Self-motivation responses included the desire to know presence or absence of TB; wanting to allay concerns about possible infection; and knowing that testing could rule out other illnesses.

2. Concern about infecting other family members was a major motivating factor as respondents did not want to be responsible for spreading the infection.

3. Knowledge that treatment is effective and that TB is curable motivated those who knew that even if they were diagnosed with TB, they could be cured.

4. Having someone to watch children or livestock removed a barrier of inability to leave home to go for testing. Home responsibilities are often the priority.

5. Many cited free testing as making it possible for them to get screened, particularly when multiple family members have to be tested.

6. Getting results quickly encouraged people to be tested to end the worry that they might be infected.

Barriers: On the reverse side, respondents identified some factors that make it difficult or impossible to seek testing.

1. Lack of time due to livelihood, child care, and household work was a major barrier. In some families called for testing, one member may miss out because s/he has to look after the children, crops, business, livestock, or perform other household duties.

Livestock care was pronounced in Naryn and some regions of Jalal-Abad, while others in the south mentioned delaying testing until the harvest was finished.

“We often go to jailoo [pasture] and it is far [to] come down. We cannot leave the animals.” (Man, 41, Chui Oblast)
“I didn’t go because I was looking after livestock and my family; there are elderly and children in the family.” (Woman, 48, Jalal-Abad)

2. Cost of X-ray, tests, and other payments were mentioned, despite the fact that testing is supposed to be free. People are sometimes sent to a private lab where they are charged and some mentioned paying for the X-ray.

“They took money from us for referral to do testing. It is far to go for testing; therefore, we have decided not to spend money, what if we would have to pay there?” (Man, 30, Jalal-Abad)

“The test was expensive in the private laboratory.” (Man, 40, Jalal-Abad)

3. Lack or cost of transport and long distances were a barrier in all regions, particularly in Naryn.

“We must go to the rayon [district] center, this is far, a lot of time is needed and you spend money.” (Woman, 63, Chui)

“It is far to the district center and we are a big family so we had to hire two cars to take us.” (Woman, 63, Naryn)

“There is no bus or marshrutka [minibus] in the village, you have to take a taxi to the family medical center and it is expensive for me.” (Man, 42, Naryn)

4. Stigma was a deterrent to seeking testing because many people do not want anyone to see them at the health center for testing. This concern of being seen and told on by a neighbor was mentioned in the focus groups. Others have faced stigma from health workers.

“People [referred for testing] are treated badly, as if you are already sick. Some doctors have this attitude. And when I was tested, I felt as if I was already sick, infected.” (Woman, 25, Chui)

The following case study of a man from a Jalal-Abad illustrates some of these difficulties to seeking testing.
Case study 1: Testing

A 40-year-old man from Jalal-Abad whose wife was diagnosed with TB had to get his entire family of seven tested for TB (his five children, his mother and himself). First they went to the family medical center to get tested, but to be sure, they did additional testing in a private laboratory. For seven people in the private lab it was quite expensive, about 500 Kyrgyz soms per person [about 50 dollars in total]. It was also complicated to go to two different facilities, but he had to make sure that his children were healthy. It was far to travel and they had to do the testing in two batches; three and then four people. The man’s brothers and sisters had to help because his youngest child was an infant. “When my neighbors found out about my wife’s illness, he says, our whole family was shunned, my children stopped playing outside with children from our neighborhood.”

Enabling factors and barriers to starting treatment

The researchers originally planned to examine three behaviors (testing, starting treatment, and completing treatment), but found that it was very difficult to find non-doers for the starting treatment category. Although national data show that there may be missing TB cases who have not started treatment, they were not found in the areas chosen for sampling in the research study because, for example, they had moved to another region, left to work in Russia or the capital city, there was nobody home, or they did not answer phone calls. As a result, the issue of starting treatment was further explored during the FGDs with health care workers and additional FGDs were planned in the field to gather more information on this topic. According to both health workers and patients, health workers do a good job of encouraging patients to start treatment immediately after diagnosis and patients are interested in improving their health. Based on health worker responses, the incentive payments they receive for successfully treated cases also play a role.

The specificity of the DND method is that researchers need to identify the difference between those who followed a recommended health practice and those who did not. The relative lack of non-doers for this category made it impossible to draw a comparison between doers and non-doers. However, the information obtained from the doer interviews on enablers and barriers for starting treatment validated the similar enablers and barriers mentioned for seeking testing.

The lack of non-doers for starting treatment is a potential finding in itself, and indicates that this behavior (starting treatment promptly after diagnosis) may not be as problematic as initially hypothesized. As a result, this behavior was dropped as a key behavior of interest in the development of the SBC strategy. The SBC strategy therefore focuses on the key behaviors of seeking testing and completing treatment.
Enabling factors and barriers to completing treatment

Each TB patient who agreed to be interviewed was asked a series of verbal screening questions at the beginning of the interview to build a short case description and better assess factors affecting adherence to TB treatment. This information added insights and made it possible to do a second, separate analysis for the responses of patients who have apparent DR-TB. Approximately half of those completing treatment and half of those not completing treatment were categorized as DR-TB. This group has some differences in perceived barriers or difficulties.

**Enabling factors:**
The factors that motivated patients and made it easier for them to complete treatment were the same between drug-sensitive TB and DR-TB patients.

1. Personal goals and a desire to be cured were the most important factor in treatment adherence. Patients said they wanted to be healthy to resume a normal life, or be cured for the sake of their children or family.

2. Concern about infecting others, particularly children or family, was a primary motivating factor.

3. Feeling better physically or psychologically after starting treatment motivated many patients, but was not mentioned by everyone.

4. Advice, information, support from health care workers was mentioned by patients as a factor that helped them comply with the treatment regime. Some mentioned specific health care workers (HCWs) who had helped them along the way; others mentioned NGO staff.

5. Convenience of the treatment regimen, such as receiving medications at home, helped patients avoid daily trips to the health facility, waiting time there, and the necessity for transport.

6. Incentives, particularly cash or food incentives, and good inpatient care were mentioned as helpful by some patients. For instance, financial help to cover transportation costs was an enabling factor. Some patients noted good care at the hospital, which included good food, heat, constant monitoring of treatment and side effects by HCWs, and treatment for co-morbidities.

**Barriers:**

1. Adverse reactions of treatment included both the immediate side effects of taking the medicines and the longer-term adverse reactions. Many patients mentioned side effects consistent with regular TB treatment, but DR-TB patients cited more.

2. Patients mentioned the difficulty of swallowing large pills or having to take a large quantity of tablets at one time. Many said they would prefer injections.
3. Family issues that interfere with treatment include being abandoned by a spouse, having family members with other illnesses, having children to care for, or a death in the family, with the associated emotional and logistical difficulties.

4. Alcohol dependence is a major barrier to treatment adherence, not only for high-risk groups, but for the whole study population. It is particularly a challenge for DR-TB treatment and for people who do not have a home, but many patients living with family also suffer from alcohol dependence and interrupt treatment. Alcohol dependence of other family members was mentioned when patients lacked support at home to continue treatment. Several people remarked that “it is better to drink alcohol than to take the TB drugs.”

5. Co-existing illness or injury hampers treatment, particularly when the patient loses mobility and has to go to the health facility for medicines.

6. Inconvenience of going to health facilities every day and the need to travel for tests was frequently mentioned as a complicating factor of treatment.

   “I have to take two marshutkas to get to the family group practice and it takes most of the day to go and return.” (Man, 70, Chui)

   “It is difficult to go there every day, it is hard especially in winter, and sometimes I had no money for taxi.” (Woman, 25, Chui)

7. For high-risk groups, particularly internal migrants, former prisoners, and people who are homeless, lack of registration and other factors specific to the general population were major barriers to treatment. As many as half of the households in the new settlements (novostroiki) may not have registration. Some are given temporary documents to seek health care, but say health workers treat them poorly because they lack permanent registration. Some reported paying for treatment.

   “They [medical workers] are disrespectful, as if I had moved from another country.” (Woman, FGD internal migrants, Bishkek)

   “All the money my husband earned was spent on my treatment, not daily living. We paid for droppers, inhalers, X-rays, medicines, everything.” (Woman, 22, internal migrant, Chui)

8. Treatment length was a complicating factor cited by many DR-TB patients. It is linked to other problems such as having to go to the health facility every day during long-term treatment, and not being able to work while on treatment, and thus, financial difficulties.

The following case study of a woman from Jalal-Abad who did not complete treatment for drug-resistant TB illustrates some of the personal difficulties and barriers to completing treatment.
Case Study 2: Treatment

A 34-year-old woman from Jalal-Abad got sick with TB in 2015 and was treated in a TB hospital for 6 months. She did not continue taking drugs on an outpatient basis after that because she thought she was cured. She got sick again in 2017, and was in hospital for two years. When she suffered a tragedy—her 10-year-old son died—she interrupted treatment again. Her general state had improved while she was in the hospital. Now she is very thin, cannot walk, has sore legs, suffers from tachycardia, shortness of breath, and nausea, and her skin has blackened [from the drugs]. She is very weak and cannot cook for herself. Her children, siblings and relatives help her.

Sources of support
The DND tool also enables researchers to identify who supports (or does not support) individuals to seek testing or start and complete treatment. Emotional and/or financial support helps patients adhere to treatment. The two main supporting groups identified in the study are family and HCWs.

The large majority of people interviewed have solid support from immediate family. Many receive emotional and financial support. Many also have support from more distant relatives and neighbors. There were cases in which in-laws sent young wives back to be cared for by their parents after TB diagnosis. External migrants receive encouragement from family members; some are advised to come home for treatment, sometimes even receiving money to pay for their travel.

Many patients in each oblast mentioned support from HCWs. Study participants often mentioned the name of a doctor or nurse from the hospital or another health facility who was particularly supportive. Patients mentioned receiving advice, encouragement, and links to other services from NGOs or local authorities.

“Health care workers, the family group practice nurse, our TB doctor [supported me to complete treatment]. I could call them anytime. The surgeon from the National TB Center supported me greatly.” (Woman, 28, internal migrant, Chui)

Members of high-risk groups such as former prisoners and internal migrants mentioned NGO support. People who are homeless were least likely to have any support, other than from peers who may exert negative influence, by for example, suggesting the patient resume drinking alcohol.

Stigma
Stigma is recognized as a major factor in the dynamics of tuberculosis worldwide. The main technical partners in the field of TB control, including WHO, the Stop TB Partnership, and the Global Fund, recommend policies to counter stigma to reduce barriers to treatment and reduce discrimination against people with TB. The word stigma means a “sign, or mark of shame.” Stigmatization is to label someone in a negative way, which can lead to
discrimination against that person not only by the community, but also in the delivery of health care services.

This study took a multi-pronged approach using several tools, described earlier, to assess stigma among the general population, people with symptoms of TB, people with TB, their families, and HCWs. The effects of stigma on seeking diagnosis and completing treatment were also assessed.

In general, the study found that stigma is widespread in the country, but there are regional differences in expressions of stigma. In Naryn, FGD participants initially said that people should support those undergoing treatment. They cited strong cultural values against separating someone because of having TB.

“It is impossible to separate [someone] from the family, from the society among Kyrgyz people. We cannot shun a person because he is sick, it is wrong according to our traditions and customs.” (Man, FGD general population, Naryn)

“Our mentality does not allow us to separate members of the community. There is “yntymak” [i.e. mutual assistance and support, friendship, community] and it must not be violated.” (Woman, FGD general population, Naryn)

Probing revealed that many people were uneasy around people with TB and felt that precautions must be taken to prevent infection. At the same time, they did not want the person to know or sense that they took measures to prevent infection.

“We can’t tell the patient himself, but we are still afraid. After him, we clean everything.” (Woman, FGD general population, Naryn)

Some of the stigma comes from stereotypes about who is likely to get TB. FGD participants in each region mentioned persons in difficult or undesirable life situations. Those most frequently mentioned included prisoners, smokers, people with alcohol dependence, poor people, and people with poor hygiene.

“Poor people, because they do not have the opportunity to visit the hospital and eat poorly.” (Woman, FGD general population, Naryn)

“Alcoholics get sick, because when they drink, they stay in the cold for a long time and lie in different damp and cold places. Do not look after themselves, do not eat well.” (Woman, FGD general population, Naryn)

“I thought that only prisoners could get TB. Many people think so.” (Woman, FGD general population, Naryn)

Types of stigma identified
There are various types of stigma described in the literature on stigma and our study found three of them—public, perceived, and self-stigma—among TB patients and their
communities. There was also mention of a fourth type, called secondary stigma, among HCWs.15

Public stigma
Public stigma is the view of the general population about TB patients. Sometimes stigma is enacted through discriminatory actions. In this study, participants primarily mentioned shunning or avoiding the affected person and family, but also talked about gossiping and feeling uncomfortable around a person with TB. Participants also told stories about families with TB that were asked to leave the community and spouses who abandoned partners with TB.

“There is a risk of infection, so you need to be careful with TB patients.” (Woman, FGD internal migrants, Bishkek)

“They may warn children from playing with children from the families with a TB patient. We would say so as well.” (Woman, FGD general population, Chui)

“If the patient will be treated then he can work as usual. However, the management may dismiss him from work due to the fear that he can be contagious.” (Woman, FGD general population, Chui)

“I was even invited to such a house, but my relatives did not let me go, as they were saying that you don’t know whether it is open or closed form [of TB]. Even relatives stopped going, not to mention the neighbors.” (Woman, FGD, general population, Naryn)

“The attitude of people becomes different. They will not sit down at one table with the patient; they will not eat from one dish.” (Man, FGD general population, Jalal-Abad)

“Every time when I remember it, I feel bad. I suffered misunderstanding from the neighbors. Grandchildren had troubles at school, they were teased. Many of our friends stopped inviting us to feasts and holidays.” (Woman, 73, stigma DND, Jalal-Abad)

Another serious consequence of stigma is the loss or decrease of marriageability of the son or daughter from a family in which there is or has been TB.

“Girls must not be married to a patient. We need to think about the future of children. But if everything is already okay with his health, then we need to think and discuss.” (Man, FGD general population, Naryn)

“If in a family a girl gets sick with TB or had TB and she is going to get married, then most likely, the parents of the groom will be against it. Even if the bride herself was not sick, but one of her relatives, people will still think that there will be consequences... They are afraid of unhealthy offspring; they may be afraid of the birth of impaired children.” (Woman, FGD general population, Naryn)

“It is good that their sister got married before [her brothers got] TB, otherwise no one would have married her if it was known.” (Man, FGD general population, Jalal-Abad)
Perceived stigma
In perceived (subjectively felt) stigma, the patient or the family thinks that others are stigmatizing them. Regardless of how they are treated, they suffer from imagined or anticipated avoidance, gossip, and rejection. This form of stigma was highly prevalent among the TB patients and families interviewed for this study.

“If you have TB, you are not a person. You will feel a biased attitude from others, so that you yourself will want to be away from them.” (Woman, FGD general population, Jalal-Abad)

“A neighbor, whose husband had TB before, was saying, ‘When I used to walk along the street, they would be whispering behind my back, I felt bad because of it. People spoke different things about us. On the way to the doctor, they would gossip. I was crying a lot, lost my courage.’” (Woman, FGD general population, Jalal-Abad)

“I am afraid of bad attitude of neighbors and people. As soon as they will find out about our misfortune, they will start to shun us.” (Woman, 73, stigma DND, Jalal-Abad)

“I am afraid of judgement by neighbors and relatives, especially from my husband’s side.” (Woman, 42, stigma DND, Jalal-Abad)

“It is a stress to everybody in the family. There will still be judgement. I am afraid that they will talk about my family, that we have a TB patient as I have children.” (Woman, 51, stigma DND, Jalal-Abad)

“If we share this unnecessary information, it will be difficult then to marry off daughter or son.” (Woman, 79, stigma DND, Jalal-Abad)

“People are far from happy to accept the news that someone has TB, this is not accepted. I also do not want to be asked about this, it hurts me to talk about it.” (Woman, 70, stigma DND, Jalal-Abad)

Self-stigma
Self-stigma occurs when a person with diagnosed TB chooses to isolate. The study found many reports of this from individual patients, families, and HCWs. They cited two main reasons for this self-isolation: one is fear of spreading the illness to family members and other people; the second is fear of a negative reaction from distant relatives and neighbors. Self-stigma includes feeling bad about oneself, including a long-term loss of self-esteem characterized by pessimistic attitudes toward future employment and social prospects.

“Our neighbor had TB. He himself started to shun others. We told him that it is not necessary, but he didn’t change his mind. Everyone is invited to the common events, but he himself was uncomfortable, he wouldn’t sit at the common table, would start to put on a mask.” (Man, FGD general population, Jalal-Abad)

“I am afraid of infecting my children. While I am on treatment, I have moved to another apartment by myself.” (Man, 49, TB patient DND, Chui)
“It depends on the person himself how he will perceive the news about the disease. They can say - you are sick, and a person shrinks into himself, stops believing, hides, closes himself up.” (Woman, FGD general population, Jalal-Abad)

“The patients stigmatize themselves, are afraid they will be seen in the clinic...” (HCW, FGD, Chui)

“I am afraid that people will shun me, as my husband is sick and they believe that I can be infected from him and infect others. It’s easier for yourself, the fewer people will know, so the less questions will be asked and there will be less sideways looks.” (Woman, 54, stigma DND, Jalal-Abad)

Secondary stigma
Secondary stigma is sometimes applied by society to HCWs and others who care for TB patients. This type of stigma was probed for in FGDs with HCWs, who were asked what fellow health workers think about TB patients and about their working with them. They were also asked what their families and neighbors think about them working with TB patients. Most felt no stigma from other HCWs, although a couple of instances of secondary stigma were mentioned.

“When the TB cabinet nurse invited others [health workers] to tea in our space, they didn’t want to come.” (HCW, FGD, Chui)

“Colleagues, among themselves, call our TB patients, ‘your tubiks’ [derogatory term for TB patients].” (HCW, FGD, Chui)

“Those colleagues who work with TB patients understand everything and are normal, those who do not encounter TB patients in their work, behave [toward them] with wariness.” (HCW, FGD, Chui)

“We can tell our closest family members that we work with TB but friends or distant relatives do not know, they know only that I am a nurse.” (HCW, FGD, Jalal-Abad)

“Relatives usually don’t know that I work with TB. When they find out, they feel aversion.” (HCW, FGD, Chui)

Overall, most patients were very satisfied with the attitudes of the TB doctors and nurses. A few reported discrimination from health workers, especially the so-called “narrow specialists” to whom they are referred for treatment of specific conditions or side effects.

“They make us wait until the entire queue has passed.” (Man, 22, TB patient DND, Jalal-Abad)

“Narrow specialist doctors treat us rudely.” (Man, 37, TB patient DND, Bishkek)
Stigma as a barrier to seeking diagnosis or completing treatment

In discussing whether to seek testing, some study participants mentioned concern about other people finding out that they were being tested for TB, but this concern was not keeping them from being tested. Many others said they would not tell anyone they had been screened for fear of other people’s reaction.

When describing the many challenges to completing treatment for TB, stigma was not identified as a barrier. However, people said that effects of stigma made their treatment more difficult, for example, several people with self-stigma were without support of family or friends for the duration of the treatment. Others were unwilling to let anyone know of their TB treatment, even though they could have benefitted from emotional and financial support.

While stigma or fear of stigma may not have been direct barriers to seeking diagnosis or completing treatment, its effects, particularly lack of social support, may seriously undermine the quality of life for TB patients and their families. Whether real or perceived, stigma causes stress and disconnects patients and families from usual social interaction, both of which may have lingering effects that will reduce the person’s resumption of a normal, productive life.

Causal analysis for stigma

The fundamental concept of stigma is that the labeled person is given an identity different from the rest of the community or population. The creation of this different, dangerous identity creates fear. Generating fear of the ‘marked’ person is an essential step in forming stigma. Many times, this results from amplifying or exaggerating the risk that a disease or condition poses to society. Findings from our research exemplify the exaggeration of risk of contagion of TB. The fear of contracting TB from someone is the ultimate reason underlying TB stigma in Kyrgyzstan.

“Once upon a time [i.e., during Soviet times] they raised awareness among people that this terrible disease is not curable, be very careful. And still, despite the fact that new information on TB is given, old attitudes still prevail. In addition, we hear about deaths from TB and this is a confirmation of the old attitudes. Someone is cured, but this is not visible, but if someone has died, it is seen (visible).” (Woman, FGD general population, Naryn)

“Not only neighbors, even other family members will fear to be infected.” (Woman, FGD general population, Jalal-Abad)

The focus groups revealed an abundance of misinformation about how TB is contracted and its transmission. Many said it is transmitted on dishes, through saliva, and on clothing. This is such a concern that some families separate dishes and wash clothing of the person with TB separately. Some said it could be transmitted through handshakes or kisses. Others said it is inherited (genetic).

Many people also express doubt that TB can really be cured and that a person is no longer infectious after two weeks of treatment. Perhaps as many as half of FGD participants were
unsure that TB can be cured. Below are some common examples of misconceptions about TB mentioned during the research.

**Table 2. Examples of Misinformation about TB**

<table>
<thead>
<tr>
<th>Causes</th>
<th>Transmission</th>
<th>Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>If the lungs are weak</td>
<td>Through saliva</td>
<td>Requires a long stay in the hospital</td>
</tr>
<tr>
<td>After a cold or pneumonia</td>
<td>On dishes or clothing</td>
<td>Drugs are not so effective</td>
</tr>
<tr>
<td>If your feet are cold for a long time</td>
<td>On food, including unwashed fruit</td>
<td>Cannot be cured, it always returns</td>
</tr>
<tr>
<td>It can be inherited</td>
<td>Through spitting/sputum</td>
<td>There is chronic TB</td>
</tr>
<tr>
<td>We all have “rods” [bacilli] that can convert (change, “wake up”)</td>
<td>From kisses</td>
<td>Can only be cured if good nutrition</td>
</tr>
<tr>
<td>Sleeping where it is damp and cold</td>
<td>From dentist’s unsterile tools</td>
<td>Spots on the lungs always remain</td>
</tr>
<tr>
<td></td>
<td>In the bath house</td>
<td>Patient can always infect others</td>
</tr>
<tr>
<td></td>
<td>Not through the air (or we would all have it)</td>
<td>Treatment at home is dangerous</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Can be cured with folk medicine (consuming meat or fat from badgers, dogs, or bears; kumiss [fermented mare’s milk])</td>
</tr>
</tbody>
</table>

Figure 1 illustrates how fear leads to stigma and its social consequences in the studied oblasts. Community-level factors that cause concern about TB include misconceptions about transmission, disbelief in the curability of TB (which means even cured TB patients are forever associated with the stigma of TB), and stereotypes about people who get TB. These factors lead to both an exaggerated fear of contagion, and fear of being socially labelled by association. Personal-level factors for TB patients include fear of infecting others and being rejected by others, which often leads to TB patients self-isolating or avoiding others to preemptively avoid any expressions of stigma. Extreme downstream consequences or manifestations of this stigma at the social level include abandonment by family (divorce, rejection by in-laws’ family); impact on marriageability of people with TB or their family members; and at the individual level, self-stigma, including long-term loss of self-esteem, for people with TB. The diagram below illustrates these pathways.
Health care workers and some community FGD participants thought that TB-related stigma was lessening. Health care workers cited increasing numbers of people coming voluntarily for testing and being interested in starting treatment. Other people in the focus groups said that there is less fear now due to more available information and examples of people being cured.

“Previously, a person with TB and all his family was not liked much; we did not even greet them at a meeting. And over the past 5 years, it has become clear that TB is being cured and the attitude toward patients has become different. They are talking on TV, there is internet, a lot of information has become available.” (Man, FGD general population, Jalal-Abad)

“Now, there are practically no patients who do not take the pills. Now the consciousness of patients has also changed. They themselves are interested, they do tests and do everything voluntarily. They are interested in their health.” (HCW, FGD, Jalal-Abad)

Regional differences
In the analysis of the DND interview data, few differences overall were found between oblasts and different population groups, though some differences exist. For example, people in Naryn have more difficulty with travelling long distances to seek services, and thus experience barriers of travel cost and finding transport. In Chui, where there has been an ambulatory treatment model, doers identified outpatient care as an enabling factor for completing treatment.

Stigma was expressed differently in the north (in Naryn) versus the south (Jalal-Abad). In Naryn, the concept of community support, harmony, and honor described above meant that
even if people tried to protect themselves from transmission from a person with TB, they did so in such a way that the person would not know or feel stigma. This included separating dishes without telling the other person (even within a household) and cleaning up after the person left. In one focus group in Naryn, people explained that everybody knows who has TB immediately after they are diagnosed, but they pretend not to know. In contrast, in the south, people openly expressed uneasiness, if not outright stigma, about contact with a person who has TB. Stigma was expressed in a much more direct way, with less concern for the person finding out or becoming offended as a result.

Hypotheses and findings by target group
During research planning, Cure Tuberculosis Project staff developed several hypotheses about the different groups that were to be studied. These hypotheses were established based on previous related research studies in Kyrgyzstan. Table 3 shows the hypotheses for each group and the corresponding findings of the study.

Table 3. Hypotheses by Group and Findings

<table>
<thead>
<tr>
<th>Group</th>
<th>Hypotheses</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>General population (men)</td>
<td>Men may be less concerned about stigma.</td>
<td>Men were not as vocal about stigma but expressed concern about contagion.</td>
</tr>
<tr>
<td></td>
<td>Men may have more access to factual information on treatment than women.</td>
<td>Men did not have more factual information than women and had similar misinformation about treatment and transmission.</td>
</tr>
<tr>
<td>General population (women)</td>
<td>Women may be more concerned about stigma than men.</td>
<td>Women are very concerned about stigma of all kinds, more so than men.</td>
</tr>
<tr>
<td></td>
<td>Lack of autonomy in finances and decisions may hinder women seeking diagnosis or treatment.</td>
<td>None of the women interviewed mentioned lack of autonomy as a barrier to testing or treatment.</td>
</tr>
<tr>
<td></td>
<td>Household obligations take priority over personal health.</td>
<td>In some cases, women mentioned household obligations were a barrier to care-seeking.</td>
</tr>
<tr>
<td>External migrants</td>
<td>Working abroad takes priority over health (personal feeling or family pressure), so they interrupt treatment if diagnosed.</td>
<td>More migrants returned home for treatment than interrupted treatment to work abroad.</td>
</tr>
<tr>
<td></td>
<td>Fear of losing job prevents seeking care.</td>
<td>Most migrants are supported by family and colleagues to seek diagnosis. Some worry about job loss.</td>
</tr>
<tr>
<td></td>
<td>Lack of access to services to seek diagnosis or receive treatment abroad.</td>
<td>Access to health care services in Russia has greatly improved, but most prefer to return home for treatment.</td>
</tr>
<tr>
<td>Group</td>
<td>Challenges</td>
<td>Barriers</td>
</tr>
<tr>
<td>--------------------------------------------</td>
<td>---------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Internal migrants</td>
<td>Lack of registration may impede access to TB diagnosis and treatment.</td>
<td>Lack of registration was cited as a barrier to seeking testing and treatment.</td>
</tr>
<tr>
<td></td>
<td>Limited resources, having to work makes it difficult to seek health care.</td>
<td>Some told of being charged for treatment, many were working long hours.</td>
</tr>
<tr>
<td></td>
<td>Fear stigma (social interaction, loss of job)</td>
<td>Fear of stigma was no greater among internal migrants than among the general population.</td>
</tr>
<tr>
<td>People who are homeless, PLHIV, people who misuse alcohol</td>
<td>Lack of registration may impede access to TB diagnosis and treatment.</td>
<td>Lack of registration is a barrier to seeking care.</td>
</tr>
<tr>
<td></td>
<td>Lifestyle leads to interruption of treatment.</td>
<td>Alcohol dependence, not only for those who misuse alcohol but also for people who are homeless and others who misuse alcohol in the general population, is a major barrier to completing treatment particularly for DR-TB.</td>
</tr>
<tr>
<td></td>
<td>Lack support systems</td>
<td>Many lack family support and depend on peers for support. Peers are often opposed to treatment.</td>
</tr>
<tr>
<td>Former prisoners</td>
<td>Lack of registration may impede access to TB diagnosis and treatment.</td>
<td>Many former prisoners find it difficult to complete registration.</td>
</tr>
<tr>
<td></td>
<td>Lack of support system</td>
<td>Former prisoners have support from family, peers, NGOs, and HCWs.</td>
</tr>
<tr>
<td>HCWs</td>
<td>Attitudes toward TB patients may influence acceptance of treatment.</td>
<td>Many patients spoke very favorably of support from the HCWs encountered in TB treatment.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Some mentioned rudeness or stigma from non-TB specialists.</td>
</tr>
</tbody>
</table>

**Gender aspects**

It was very important for women, especially of a young age, to fulfill family responsibilities (housework and childcare). Men were most often busy with household/livestock care, which hindered their ability to be tested in a timely manner. At the same time, the responsibility for testing all family members and monitoring treatment of TB patients, and compliance with diet and rest, often falls to women.

Alcohol dependence is a major problem for treatment adherence, especially among men. People who are incarcerated, who use drugs, and who are homeless are also more likely to be male.
In general, the study showed that societal stigma is widespread in the country. There were cases when a husband’s family sent the young wife with TB back to her parents, who supported her. FGD participants also shared stories about spouses deserting a partner with TB. Though there were examples of both situations, this most often applied to the husband abandoning the wife. One of the most serious consequences of stigma is refusal to marry a person from a family where there is or was TB; this was more often mentioned in relation to girls.

Women were more concerned about stigma of all kinds than men, especially related to the attitude of husband’s relatives, marriage prospect of children, and effects of TB on descendants. Men were not so explicit about stigma, but expressed concern about contagion.

An important finding was that none of the women interviewed mentioned the lack of independence as a barrier to testing or treatment.

Among women in the focus groups, there was a greater interest in attending gatherings on TB and sharing information with others, as reflected in the following comments:

“If there is a good topic and it will be interestingly told then people will come to the meetings.”
“Tuberculosis is an interesting topic for me.”
“More moms will come to the meetings.”
“I will share the information received at the meeting with my children, and they will share with other children.”

Communication channels and formats
The research study asked focus group members and individuals how they could get accurate information about TB. Participants suggested that information in a simple and understandable language be disseminated during meetings, assemblies, and conversations, although they noted that people often receive information through the internet and television. They also said that stories featuring patients themselves were the most compelling. Women also noted the importance of working with youth and schoolchildren. The following quotes from an FGD with women in Naryn illustrate attitudes about sources and channels of information.

“It is better to give information through meetings. After all, housewives do not know less, but we sit at home.”
“The information in the videos is somehow far from being intelligible, conversation is a better way of informing.”
“We want to receive new information. We don’t need brochures and booklets, it doesn’t suit us. We just throw them away without reading. Live communication is better.”
“We want information to be told in a simple, non-medical language. Otherwise, it’s written in difficult language in brochures.”
“It is important that information is provided in schools before someone will have an illness.”
“At school you need to hold meetings in a very simple language. The child will surely bring home the information that he received through the conversation.”
“Young people better absorb new information.”
“Now we have begun to watch more the internet, news on television, Malysheva (Russian channel on health), health programs. The stories with the participation of the patients themselves are most impressive; it is clearer.”

Discussion

Gender
Study results suggest gender equality in access to factual information on TB, compared with the original hypothesis of better access for men. At the same time, both sexes have similar misinformation about treatment, curability, transmission and enabling factors. In addition, none of the women interviewed mentioned a lack of financial independence or decision-making authority as a barrier to seeking medical care for diagnosis or treatment, contrary to the original hypothesis.

Target groups
Focus group discussions with labor migrants and their families indicate that recently there have been more instances of migrants interrupting work abroad to return to Kyrgyzstan for treatment, rather than migrants interrupting treatment in Kyrgyzstan to go for work abroad. This seems to point to an improvement in the level of awareness about TB, its curability, and the possibility of getting free treatment at home. An important enabling factor that they cited was support from family and colleagues for testing and treatment in Kyrgyzstan. Notably, work and living conditions among Kyrgyz migrants abroad seem much better now than in previous years, and compared to previous studies of TB among labor migrants in Central Asia. Migrants cited better regulation of work conditions and registration, and access to health services through mandatory insurance. In addition, FGD participants said that there have been some attitude and behavior changes in society in relation to TB patients and their treatment, thanks to increased information in recent years, but this work needs to be continued.

Role of health workers and patient-centered care
Many patients in each oblast mentioned support from HCWs. This finding may be somewhat biased since the interviewees knew the researchers were in contact with health workers, but the study participants often mentioned the name of a particular physician or nurse from the hospital or another health facility who was particularly supportive. Patients mentioned receiving advice, encouragement, and links to other services from NGOs or local government. This indicates the central role of HCWs in patients’ treatment completion, which should be emphasized in communication campaigns and activities with health workers. Overall, the multiple barriers to care and treatment that people with TB experienced underline the importance of designing patient-centered strategies that allow patients to receive treatment in ways that are convenient and help them adhere.
Regional differences
Respondents in Naryn often cited more barriers to testing and treatment related to the long distances required to travel to the nearest health facility, and the corresponding transportation and opportunity costs of time away from work or household responsibilities. This is especially true in rural areas where distances are great and transportation options limited. This points to the importance of transportation or other monetary incentives, especially for people who live in rural areas. It also underlines the importance of people-centered models of care, including community-based treatment, for people who have difficulty accessing health services.

There were also regional differences in the way stigma was expressed. As described earlier, communities in Naryn often referred to traditional concepts of community and mutual support in relation to how people with TB should be treated. While people were afraid of being infected and took necessary precautions, they often did so in such a way as to not openly stigmatize the person with TB for fear of offending them. In contrast, in the south (Jalal-Abad), stigma against TB patients was much more openly expressed. One reason for this may be that in Jalal-Abad, population density is much higher, which means that the possibility of contagion within communities could be greater. In contrast, in Naryn where distances are very large especially in remote rural areas, people may be forced to rely more heavily on neighbors and other families for support and therefore be more careful about antagonizing each other. There may also be cultural differences which affect how stigma is expressed: the ethnic makeup of Naryn is predominantly Kyrgyz with semi-nomadic roots, whereas Jalal-Abad is a more sedentary population with large Uzbek communities.

In Chui Oblast in particular, respondents identified the outpatient treatment model as an enabling factor for completing treatment. This could be due to the fact that in Chui, outpatient treatment was introduced much earlier than in other regions, so more people may be informed about and using those services. The system might also be working better because it has been in place longer. This highlights again the role of patient-centered treatment options to support treatment completion.
Conclusions
The main findings of the research study are summarized below.

1. **Enabling factors for TB testing**: self-motivation and a desire to know one’s TB status; concern about infecting other family members; knowledge that treatment is effective; having someone to help look after children, home, and livestock while gone for testing; access to free testing, especially when several family members need to be tested; and rapid results.

2. **Barriers to TB testing**: lack of time due to livelihood, childcare, housework; the cost of X-rays and tests, and other payments; lack of/cost of transport and long distances, especially for those in rural areas such as Naryn; and stigma and concern about gossiping from people who might see them in the health facility.

3. **Enabling factors and barriers to starting treatment**: doer and non-doer behaviors could not be compared for the starting treatment category because it was difficult to find people who were diagnosed with TB but did not start treatment. This indicates that starting treatment is not as much of a problem as originally hypothesized, so it was dropped from the SBC strategy as a key behavior of interest. Additional information on this issue collected from focus groups indicates that health workers do a good job of encouraging patients to start treatment immediately. The enablers and barriers mentioned for starting treatment were similar to those for testing described above.

4. **Enabling factors for completing treatment**: having personal goals and a desire to be cured; having concern about infecting others, especially children or family; feeling better physically or psychologically after starting treatment; advice, information, and support from HCWs or NGO staff; convenience of the treatment regimen such as taking pills at home and avoiding daily trips to the health facility; and receiving some kind of incentive (financial or food), as well as good inpatient care.

5. **Barriers to completing treatment**: adverse reactions from treatment especially for people with DR-TB; difficulties related to drug intake (swallowing large and/or large quantities of pills at one time); family issues (including divorce or spousal abandonment, family members with other illnesses, children to look after, and death in the family); alcohol dependence, especially among DR-TB patients and people who are homeless; co-existing illness or injury that hampers mobility; inconvenience of daily trips to health facilities or travel for testing; lack of registration for high-risk groups, especially internal migrants, former prisoners, and people who are homeless; and length of treatment, especially for people with DR-TB.

6. **Sources of support**: many respondents indicated the family as a source of emotional and financial support. Many patients in each oblast noted support from HCWs. Patients also mentioned receiving advice, encouragement, and referral to other services from NGOs or local authorities.
7. **Identified types of stigma:** The study revealed three types of stigma—public, perceived and self-stigma—among TB patients and their communities, and secondary stigma towards health workers who treat TB patients. While stigma or fear of stigma may not have been found to be direct barriers to testing or completing treatment, its effects, particularly lack of social support, may seriously undermine the quality of life for TB patients and their families. Whether real or perceived, stigma causes stress and disconnects patients and families from usual social interaction, both of which may impede a person’s resumption of a normal, productive life.

8. **Causal analysis for stigma:** the fear of contracting TB is the ultimate reason underlying TB stigma in Kyrgyzstan, and an abundance of misinformation about TB contributes to this fear. Community-level factors that cause concern about TB include misconceptions about transmission, disbelief in the curability of TB, and stereotypes about people who contract TB. Personal-level factors among TB patients include a fear of infecting others and of social rejection, which cause TB patients to self-isolate. All of these factors lead to stigma through the pathways of fear of contagion and fear of social labelling. The most significant downstream consequences of stigma include abandonment by family, loss of marriageability, and self-isolation and self-stigma of TB patients.

9. **For high-risk groups,** especially internal migrants, former prisoners, and people who are homeless, the lack of residence registration was a significant barrier to social services and medical care, along with other factors affecting the general population. Internal migrants noted that they were treated poorly by HCWs due to a lack of registration and were sometimes even charged for treatment. High-risk groups, such as former prisoners and internal migrants, also mentioned receiving NGO support. People who are homeless are least likely to receive any kind of support, other than from peers who may exert negative influence. Alcohol dependence is a major barrier to treatment adherence for high-risk groups, especially for DR-TB patients.

10. **Gender aspects:** household responsibilities (for women - housework and childcare, for men - household/livestock care) are a barrier to seeking health care. The responsibility for testing all family members and monitoring TB treatment falls to women primarily. Alcohol dependence, a major detractor of treatment adherence, is most common among men. Women were more concerned about stigma than men, especially related to the attitude of in-laws, children’s marriage prospects, and TB’s effect on descendants. Men were less explicit about stigma, but expressed concern about contagion. Among women, there was great interest in gatherings on TB and willingness to share information with others.

11. **Health care workers:** many patients were positive about the support received from HCWs involved in TB treatment. Some respondents mentioned stigma from HCWs, particularly from non-TB specialists. There were cases when HCWs poorly explained the details of testing and patients had to spend more time and money as a result.

12. **Communication channels and forms:** respondents noted the importance of disseminating information in a simple and understandable language, focusing on the
fact that people now often receive information through internet and television. Respondents, especially women, expressed a preference for in-person meetings, gatherings, and conversations. Stories that include patients themselves are the most compelling. Women also noted their willingness to disseminate information about TB, and the importance of working with youth and schoolchildren.

**Recommendations**

Based on the formative research findings, a detailed social and behavior change strategy was developed for the Cure Tuberculosis Project addressing each of the studied behaviors, with messages and communication channels for each target group.

In tandem, the Cure Tuberculosis Project will help to create an enabling environment for timely TB testing and treatment, with a particular focus on the following points and recommendations:

- Disseminate the following information and key messages to improve knowledge and reduce stigma: information on how TB is transmitted, that TB is curable, that most people are no longer contagious after the first two weeks of treatment, that TB can be cured only with TB drugs, that TB treatment is free, and that it is important to complete the full course of treatment.

- Improve communication and care from the family, HCWs, community, local authorities, and NGOs in order to provide support for testing of people with presumptive TB and to enhance treatment adherence of TB patients.

- Train and mentor HCWs, given their essential role in TB detection and treatment support, to counsel TB patients on where to go for testing, care, and treatment, how to protect other people, how to continue social life, what to do in case of adverse reactions due to taking TB drugs, etc.

- Develop information and counselling skills among HCWs, staff of partner NGOs, and staff of homeless shelters through training and subsequent support and mentoring. Consider advocacy for regular TB screenings for risk groups within homeless shelters and regular follow-up for treatment.

- Develop and implement approaches to practice infection control measures at home and involve TB patients in the treatment process.

- Develop targeted messages in simple and non-medical language for the main target and high-risk groups, taking into account communication channel preferences.

- Communicate with the general population and risk groups through a combination of media, including mass media, social media and interpersonal communication, and engage famous personalities and decision-makers in SBC activities.

- Promote TB patient stories of cure and return to normal life in the community, work, or school, through various media channels.
• Develop gender-sensitive SBC approaches and tools to take into account differential barriers to care and roles for men and women and specific risk factors for men, in designing tailored case management approaches; and disseminate positive narratives through behavioral journalism approaches that dispel misconceptions that are particularly harmful to women, such as inheritability of TB and effect on marriageability.

In addition to the specific SBC activities to be undertaken by the Cure Tuberculosis Project, support and services for TB patients need strengthening to minimize barriers to testing and treatment and to improve treatment adherence. Some of these efforts may not be possible in the short-term, but can be promoted for the future. This national-level effort involves working with the NTP and all partners to:

• Scale up experience in implementation of community-based DOT (including video observation of TB drug administration) across the country, particularly in rural areas with difficulties in access to services.

• Scale up the implementation of the TB case management approach and payment mechanisms for successfully treated cases in all regions of the country.

• Promote and adopt advances in medications that are more convenient to take and have fewer side effects, and incorporate these into the treatment regimen in the Kyrgyz Republic.

• Highlight the importance of TB patient motivation and support in treatment adherence, which may include food and monetary incentives. As these incentives are currently primarily funded by donor programs, advocate for alternative financing mechanisms to improve financial sustainability of this important support, including through local government financing.

• Orient all health care staff, including non-TB specialists, and update all medical curricula with current TB treatment guidelines and content on the importance of reducing stigma and discrimination of TB patients.

• Pay special attention to alcohol misuse as one of the major barriers to completing TB treatment. It is important to provide patients who misuse alcohol with alternative types of DOT (such as a community-based treatment supporter) and advocate for the promotion of prevention and treatment of alcohol dependence.

• Advocate for simplification of the process for accessing TB services without residence registration, especially for internal migrants and other high-risk groups who do not have permanent registration.
Annex 1. Situation Analysis of Key Risk Groups

Certain vulnerable groups are more susceptible to contracting TB and experience barriers to care and treatment, which often affect treatment adherence and cause worse outcomes. The existing literature on risk groups in Kyrgyzstan and their difficulties related to TB care is summarized below.

**Barriers to diagnosis**

Factors generally associated with diagnostic delay for TB include alcoholism, substance misuse, rural residence, poor access to health care, poverty, poor knowledge of TB, and stigma.24 One qualitative study of barriers to care-seeking behavior among high-risk populations in Kyrgyzstan included absence of identification documents, lack of money for diagnostics and treatment, stigma, and low perception of symptom seriousness.25 A quantitative study of diagnostic barriers in Kyrgyzstan found a mean diagnostic delay of 36 days from onset of symptoms to first contact with the health system. The factors associated with delay included age over 61, migration, and rural residence. Protective factors against delayed care-seeking include education, knowledge of TB symptoms and transmission, and availability of public transportation.26

**Barriers to treatment**

One qualitative study among TB/DR-TB patients in Osh Oblast found that vulnerable groups including people who misuse drugs and alcohol, who are homeless, ethnic minorities, and young women experience barriers in access to care for TB. The study also found that while some patients who live alone or have nobody to care for them prefer receiving inpatient treatment, many prefer ambulatory treatment thanks to the emotional support they can receive from family. Patients from vulnerable groups who experienced stigma also preferred outpatient treatment.27 Other studies from Central Asia and Eastern Europe have identified many factors associated with LTFU from TB treatment, including alcohol misuse, drug addiction, homelessness, external migration, unemployment, imprisonment, HIV co-infection, and MDR-TB.28 A study of DR-TB patients in Kyrgyzstan found that hospitalization during the intensive phase and lack of sputum conversion during the first 6 months of treatment were significantly associated with LTFU. This highlights the need for ambulatory treatment for DR-TB and special attention to people who have difficult forms of DR-TB.28

**Tuberculosis awareness and stigma**

According to the 2012 Demographic and Health Survey, there is a high degree of awareness of TB among the population (94% of women and 96% of men). Eighty percent of men and 83% of women are aware that TB can be cured. One of the lowest levels of awareness of treatability of TB was among women in Naryn (71%). Both genders had significant misconceptions about transmission, with 63% of women and 44% of men believing the disease can be spread by sharing utensils, and 32% of women and 39% of men believing it can be spread through food. In terms of stigma, 39% of women responded that they would want to keep a family member’s diagnosed TB secret, whereas only 14% of men said so. This indicates greater concern about stigma among women than men.29 According to the 2018
Multiple Indicator Cluster Survey among women ages 15–49, 84% knew that TB could be cured and 28% indicated that they preferred not to disclose a family member’s diagnosis of TB. This expression of stigma was highest in Chui Oblast (48%), Bishkek City (35%), and Jalal-Abad Oblast (32%).

In one study of socio-economic factors affecting TB care in Bishkek City, Chui Oblast, and Jalal-Abad Oblast, 18% of respondents claimed to know someone who was compelled to leave his/her family when s/he contracted TB, and 62% indicated that people would not want to eat or drink with members of a family that had a person with TB in it. Fifty-three percent indicated that they would be afraid to tell their family members about TB. In Jalal-Abad, 80% of both male and female respondents indicated they believed that women’s TB is especially dangerous for others, including family and society. Up to 44% of respondents in Chui Oblast claimed that people should not marry a woman with TB, and that a woman with TB cannot give birth to a healthy child. Forty-one percent of respondents knew someone who lost his/her job because of TB, and 17% knew someone who was forced to leave school because of TB. The same study also found that TB patients experienced stigma and discrimination, including poor attitudes, insufficient information on treatment options, harassment, and violation of patients’ rights, at the hands of the HCWs who treated them. This demotivated patients to continue treatment and undermined the credibility of health workers and their confidence in the health system as a whole.

According to a gender assessment of TB in Kyrgyzstan, TB stigma is stronger for women and has more lasting consequences in terms of reproductive possibilities as well as marriageability. Women wait longer than men to seek care and diagnosis for TB in an effort to hide the disease due to stigma, and because they prioritize other family members’ health due to their traditional roles as family caretakers.

External and internal migrants

According to the State Migration Service, at the beginning of 2019 the number of Kyrgyz citizens who left to work abroad exceeded 776,000 people, which accounts for 30% of the economically active population. Of these, 640,000 (82%) are registered in the Russian Federation, and approximately 60,000 (8%) work in neighboring Kazakhstan and Turkey, with others migrating to South Korea and other countries in Asia, Europe, the Middle East and the U.S. According to the National Bank of the Kyrgyz Republic, remittances in 2019 reached approximately $2.2 billion, representing approximately 35% of the country’s GDP. Kyrgyzstan is the second-most remittance-dependent country in the world.

In addition to external migrants, in Kyrgyzstan there is a large seasonal influx of internal and neighboring country migrants to the capital city of Bishkek and other large cities. Many of these internal migrants have settled in novostroiki (new settlements) in the suburbs of the city, often with poor living conditions. These internal migrants are often registered in their original place of residence instead of Bishkek. There is no standardized regulation for health care for people who are not residents, which causes barriers to access for internal migrants and leaves payment decisions up to individual health facilities.
Labor migrants are often at high risk of TB because of low socioeconomic status, poverty, and unemployment, which propel them into seeking work abroad or elsewhere; irregular status including residence and work permits; and often hostile situations in the receiving country. Treatment completion is particularly complicated in the context of seasonal and circular migration prevalent in Central Asia, which forces many migrants to leave and interrupt their course of treatment. This places them at higher risk of development of drug-resistant and more severe cases of TB.37 38 39

Research among Uzbek labor migrants in Kazakhstan has found that migrants are particularly vulnerable to TB due to a number of overlapping structural factors. These comprise legal factors, including undocumented status and lack of residence registration; unfavorable employment situations including informal contracts, exploitation, sequestration, crowding, malnutrition, and poor living and working conditions; and an unfavorable health care context, including barriers to access to health care, negative health worker attitudes, informal payments or bribes, and language and cultural barriers. These contexts intersect to produce both increased vulnerability to TB and reduced access to treatment, including care-seeking delays and interruption of treatment.40

One study of external and internal labor migrants with suspected TB in Kyrgyzstan found that more than half were male, and nearly half were in the 20–39 age group, which corresponds to the most active tranche of the working population. Of the cases that were confirmed with TB, 42% of new cases were rifampicin-resistant and 59% of previously-treated cases were rifampicin-resistant, both of which were higher than national statistics for that time period.41

Another study found that 45% of all registered TB cases in Bishkek were among migrants. Seventy-five percent of the migrants were unemployed; 27% were cross-border migrants, and 73% were internal migrants. Rates of treatment failure were high, as was LTFU in both new and re-treatment cases.42

One study of Central Asian migrants in Kazakhstan and Russia found higher TB prevalence rates among migrants than among general populations in either their respective countries of origin or destination. Among Kyrgyz migrants, almost half (49%) had an unregulated legal status without a valid work or residence permit, and migrants to Kazakhstan were more likely to be undocumented than migrants to Russia. Neither three-quarters (72%) stated they did not have access to a regular physician, and over one-third (38%) claimed they could not afford to pay for health services in their destination countries. In terms of risk factors, men had higher rates of smoking and drinking than women, but women faced additional barriers to care linked with childcare responsibilities.43

People living with HIV

According to UNAIDS, the estimated number of PLHIV in Kyrgyzstan in 2019 was approximately 8,500. While overall population prevalence of HIV is low (less than 1%), the HIV epidemic is concentrated among certain key risk groups and remains largely driven by injecting drug use. Prevalence of HIV is estimated at 14.3% among PWID, 11.3% among people who are incarcerated; 7% among men who have sex with men; and 2% among
female sex workers. People living with HIV are 15–22 times more likely to develop TB than persons who do not have HIV. TB is the most common presenting illness among PLHIV and is the major cause of HIV-related death.

People who are homeless

The poorest and most vulnerable groups of the population (including people who are homeless, former prisoners, people who misuse alcohol and substances, economically disadvantaged, etc.) are most likely to be exposed to TB infection, develop the disease, and have a poor treatment outcome. Based on the 2018 evaluation report of effectiveness of the Center for Social Support for TB patients in Kyrgyzstan, 86% of all people with TB who are homeless are men 40–50 years old. People who are homeless have low adherence and motivation for treatment. The most common outcome was loss to follow-up, observed in 38% of cases. A further 7.4% of patients died or were LTFU without starting treatment. TB mortality in this group (20.6%), was six times higher than country indicators among the general patients’ cohort for the same year (3.4% in 2018). The share of TB/HIV co-infection among homeless people with TB in this shelter amounted to 13%, whereas HIV infection was only 2.8% among all registered TB cases nationwide in 2018.

Prisoners and former prisoners

The estimated population of people who are incarcerated is 8,200. On average, 70 people with active TB, including those with multi-drug resistance, are released from prison annually, of whom about 50 do not reach the health care system. All of these people are in need of continuing TB treatment in the civilian health care sector. Persons released from detention facilities tend to experience many difficulties of household, medical, economic, legal, social, cultural, family, communicative, and behavioral nature. After the end of a temporary isolation period from society, especially with long sentences, people return to a changed social environment. TB treatment requires the patient to be disciplined in taking medications and regular visits to primary health care facilities. Treatment interruptions lead to the development of drug-resistant forms of TB, which require much longer treatment with many adverse reactions.

People who misuse alcohol and substances

According to the Republican Medical Information Center, in 2018, 231 people with substance addiction were registered, of whom 219 were men, and 12 were women. According to Sentinel Epidemiological Surveillance for HIV/AIDS (2016), 84% of people with substance addiction were male. In addition, in 2018, 1,163 people with alcohol addiction were registered, of whom 1,035 men and 128 women. These officially registered cases are likely to be significantly under-reported. According to UNAIDS, there are an estimated 25,000 PWID in Kyrgyzstan. Alcohol use increases the risk of TB three-fold, and is also a significant risk factor for poor TB treatment adherence. Harmful alcohol use is often concentrated among vulnerable populations and is a common co-morbidity among TB patients.
### Annex 2. Detailed Scope of Formative Research

<table>
<thead>
<tr>
<th>Proposed sites for data collection and methods to be used (tool)</th>
<th>Naryn</th>
<th>Jalal-Abad</th>
<th>Chui and Bishkek</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. SSI homeless shelter staff</td>
<td></td>
<td></td>
<td>6 individuals</td>
</tr>
<tr>
<td>2. SSI HCW prison No 31</td>
<td></td>
<td></td>
<td>3 individuals</td>
</tr>
<tr>
<td>3. Individual interview with people who are homeless, people who misuse substances, PLHIV</td>
<td></td>
<td></td>
<td>11 homeless; 1 PWID</td>
</tr>
<tr>
<td>4. SSI NGOs working with ex-prisoners</td>
<td></td>
<td></td>
<td>2 individuals</td>
</tr>
<tr>
<td>5. DND treatment completion ex-prisoners*</td>
<td></td>
<td></td>
<td>14 doers (M-12; F-2)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>4 non-doers (M-4)</td>
</tr>
<tr>
<td>6. FGD external migrants</td>
<td>2 FGDs, 21 people</td>
<td>2 FGDs, 18 people</td>
<td></td>
</tr>
<tr>
<td>7. FGD families of external migrants</td>
<td>2 FGD, 22 people</td>
<td>2 FGDs, 19 people</td>
<td></td>
</tr>
<tr>
<td>8. FGD internal migrants, new settlements</td>
<td></td>
<td></td>
<td>2 FGDs, 19 people</td>
</tr>
<tr>
<td>9. FGD/SSI health care workers</td>
<td>1 FGD, 11 people</td>
<td>2 FGDs, 18 people</td>
<td></td>
</tr>
<tr>
<td>10. FGD general women on stigma</td>
<td>3 FGDs, 30 people</td>
<td>4 FGDs, 40 people</td>
<td>3 FGDs, 27 people</td>
</tr>
<tr>
<td>11. FGD general men</td>
<td>2 FGDs, 19 people</td>
<td>2 FGDs, 22 people</td>
<td></td>
</tr>
<tr>
<td>12. DND stigma women general population</td>
<td></td>
<td>16 doers and 10 non-doers</td>
<td></td>
</tr>
<tr>
<td>13. DND seeking screening, general women across all oblasts, 10 doers, 10 non-doers men</td>
<td>17 doers (M-8; F-9) and 8 non-doers (M-5; F-3)</td>
<td>13 doers (M-4; F-9) and 9 non-doers (M-6; F-3)</td>
<td>GP: 19 doers (M-4; F-15) and 2 non-doers (M-1; F-1) Migrants doers – 4 (F-4)</td>
</tr>
<tr>
<td>14. DND starting treatment both genders</td>
<td>10 doers (M-8; F-2) and 8 non-doers (M-7; F-1)</td>
<td>17 doers (M-5; F-12) and 1 non-doers (F-1)</td>
<td>GP: 14 doers (M-10; F-4) and 2 non-doers (F-1; M-1); migrants: 14 doers (M-10; F-4), 4 non-doers (M-3; F-1)</td>
</tr>
<tr>
<td>15. DND completing treatment both genders</td>
<td>11 doers (M-6; F-5) and 9 non-doers (M-9)</td>
<td>12 doers (M-5; F-7) and 10 non-doers (M-7; F-3)</td>
<td>GP: 16 doers (M-10; F-6) and 15 non-doers (M-12; F-3); migrants: 11 doers (M-6; F-5) and 7 non-doers (M-5; F-2)</td>
</tr>
<tr>
<td>Totals</td>
<td>5 FGDs, 49 people; 63 DND</td>
<td>11 FGDs, 116 people; 88 DND</td>
<td>11 SSI 12 individual interviews 9 FGDs, 82 people; 126 DND</td>
</tr>
</tbody>
</table>

**Legend** – SSI: semi-structured interview; FGD: focus group discussion (5–10 participants); DND: doer/non-doer
* Conducted by NGOs. If possible, also conduct with homeless, 10 doers, 10 non-doers
Annex 3. Informed Consent Statements

1. Informed consent statement for semi-structured interview

*Interviewer will read the informed consent statement to the interviewee before passing it for their signature.*

Hello, my name is ________________, and I represent the USAID Cure Tuberculosis Project. We are conducting this research to study your experience and learn to what extent TB services are available for homeless/ex-prisoners with TB. The results of this study will be used to develop actions that would ensure universal and equitable access to quality TB services for different categories of population. All of the information collected today will be confidential. Your name will not be shared with anyone else. You do not have to participate if you do not want to and are welcome to end our conversation at any time. The interview may take 30 minutes of your time. If you agree to be interviewed, please sign here.

Signature __________________________

2. Informed consent statement for individual DND interview

*Interviewer will read the informed consent statement to the interviewee before passing it for their signature.*

Hello, my name is ________________, and I represent the USAID Cure Tuberculosis Project. We are conducting this research to study your experience and learn to what extent TB services are available for those in need. The results of this study will be used to develop actions that would ensure universal and equitable access to quality TB services for different categories of the population. All of the information collected today will be confidential. Your name will not be shared with anyone else. You do not have to participate if you do not want to and are welcome to end our conversation at any time. If you choose not to participate, this will not affect your eligibility for receiving health services. The interview will take less than 10 minutes of your time. If you agree to be interviewed, please sign here.

Signature ______________________________

3. Informed consent statement for Focus Group Discussion (FGD)

*Interviewer will read the informed consent statement to the participants and obtain the list of signatures of those who agree to participate in the FGD on a separate sheet of paper.*

Interviewer: “Hello, thank you for agreeing to participate in the focus group discussion. My name is ________________, and I represent the USAID Cure Tuberculosis Project. We are conducting this research to study your experience and learn to what extent TB services are available for those in need. The results of this study will be used to develop actions that would ensure universal and equitable access to quality TB services for different categories of the population.

First of all, we would like to explain what a Focus Group is. A focus group is a group discussion on pre-prepared questions, during which we are trying to understand people’s opinion on various
subjects. For instance, today we will talk about challenges that external migrants are facing for accessing TB testing and treatment. We will also discuss how to overcome these challenges.

Before we start, I would like to assure everyone that there are no right or wrong, good or bad answers. For us it is very important to get sincere and open answers, which reflect your opinion and what you really think. Please, don’t be afraid to express your opinion even if it does not match with the point of view of other members of the group or views generally accepted in society. In this regard, I would like to ask you to respect the right of everyone to have their own point of view.

If you don’t like any question you can inform us about it. You may refuse to answer any question that you are not comfortable with.

We would also like to ask whether we can make a recording of our conversation? Recording is usually done for convenience, so that later we can accurately process the results of our conversation. We assure you that these recordings and none of the information collected today will be used for any other purpose but research. I also would like to ask each of you to keep what was said in the group during the discussion private by not discussing it with others.

If there are no objections to recording then during recording and after turning on the recorder, please, do not say your names.

I would also like to ask you not to interrupt each other, but to try to speak loud, clear and one at a time. It is very important for us that everyone have the opportunity to express their opinion on the issues that we will talk about today.

The discussion will take about 1.5 hours. We will provide a small snack and drinks during the discussion.

Please, let us know if you have any question about our discussion. Does anyone have a question?”

Signature ________________________________
Signature ________________________________
Signature ________________________________
Signature ________________________________
Signature ________________________________
Signature ________________________________
Signature ________________________________
Signature ________________________________
Signature ________________________________
Signature ________________________________
Signature ________________________________
Signature ________________________________
Signature ________________________________
Annex 4. Data Collection Tools

1. Questions for staff of homeless shelters (SSI)

Oblast_______________________ District_____________________ Village___________________
Gender_______ Age _______ Education____________________________________________

Staff of homeless shelters

These interviews will be conducted with one or more staff from each of the four municipal homeless shelters in Bishkek and an NGO shelter called Fountain of Life.

Interviewer_________________________ Location:________________ Date____________

Hello, my name is __________, and I represent the USAID Cure Tuberculosis Project. We are conducting this research to study your experience and learn to what extent TB services are available for homeless people. The results of this study will be used to develop actions that would ensure universal and equitable access to quality TB services for different categories of the population. All of the information collected today will be confidential. Your name will not be shared with anyone else. You do not have to participate if you do not want to and are welcome to end our conversation at any time. The interview may take 30 minutes of your time. If you agree to be interviewed, please, sign here.

Signature_________________________________________________

1. On average, how many homeless people stay here each night? (do not ask at Fountain of Life)
2. Are most of the homeless people alone or in families?
3. Do they have any contact with family somewhere?
4. Are they registered in this city/rayon? (Probe to get an estimate of how many are not.)
5. Do they face other difficulties in accessing social services?
6. Can you estimate how many abuse drugs or alcohol?
7. Are any PLHIV among the homeless? Few or many?
8. Do some homeless suffer from mental illness? If so, are they taking medication for that?
9. We know that a doctor comes here to provide services. Does he/she test your clients for TB?
10. If someone is diagnosed with TB, where do they go to get treatment?
11. Does the shelter receive assistance from NGOs or religious people?
12. What suggestions do you have about linking the homeless people with TB screening and treatment?
Interview guide for health care staff of Prison No. 31

Oblast_______________________ District_____________________ Village___________________
Gender_______ Age _______ Education____________________________________________

Health care workers of Correctional Colony #31

Cure TB project staff will interview one or more health care staff of Prison No. 31 off-site.

Interviewer________________ No. of staff interviewed ______________ Date __________

Hello, my name is __________, and I represent the USAID Cure Tuberculosis Project. We are conducting this research to study your experience and learn to what extent TB services are available for ex-prisoners with TB. The results of this study will be used to develop actions that would ensure universal and equitable access to quality TB services for different categories of the population. All of the information collected today will be confidential. Your name will not be shared with anyone else. You do not have to participate if you do not want to and are welcome to end our conversation at any time. The interview may take 30 minutes of your time. If you agree to participate, please, sign here.

Signature _______________________________________

Please tell me about the prisoners with TB.

1. How many of those who test positive for TB refuse treatment? (Estimate) Why do you think they refuse?
2. How many are able to complete treatment while they are in prison? (Estimate)
3. Do many leave without completing treatment? (Probe for approximate percentage). Why?
4. When these people leave, do you counsel them about continuing treatment? If so, what do you say to motivate them?
5. Do you get their contact information to give to health clinics outside?
6. What barriers do you think they encounter to continuing their treatment?
7. What ideas do you have to help health workers and NGOs follow-up with these ex-prisoners?
3. Interviews of homeless people, people who misuse substances and PLHIV

Oblast_______________________ District____________________ Village____________________
Gender_______ Age _______ Education____________________________________________

**Homeless people, people who misuse alcohol and substances, and people living with HIV**

These are individual interviews to be conducted with convenience samples of the high-risk populations. The NGOs will identify the individuals through their networks using minimum criteria described in the protocol.

Interviewer________________ Bishkek or Chui (Circle one location) Date_______________

Hello, my name is __________, and I represent the USAID Cure Tuberculosis Project. We are conducting this research to study your experience and learn to what extent TB services are available for those in need. The results of this study will be used to develop actions that would ensure universal and equitable access to quality TB services for different categories of population. All of the information collected today will be confidential. Your name will not be shared with anyone else. You do not have to participate if you do not want to and are welcome to end our conversation at any time. If you choose not to participate, this will not affect your eligibility for receiving health services. The interview will take less than 10 minutes of your time. If you agree to be interviewed, please, sign here.

Signature_________________________________________________

Questions for people who misuse alcohol and substances and PLHIV:

1. Do you have family and people who are close to you?
2. Where do you live? How long have you been living there?
3. With whom do you live?
4. How do you move about? (access to transport)
5. What kind of identification documents do you have?
6. What do you know about mechanisms to restore documents?
7. What makes it difficult to maintain good health?
8. Do you have a mobile phone? If not, how do you communicate with family?
9. Do you access Facebook, YouTube, or any other social media? Which ones?
10. Where do you get information from? (television, newspaper, people)

Questions for homeless people:

1. Where do you sleep? How often do you sleep in this place?
2. Where do you go in the daytime?
3. Do you spend time with the same people every day? Who are they?
4. How do you move about? (access to transport)
5. What kind of identification documents do you have?
6. What do you know about mechanisms to restore documents?
7. What makes it difficult to maintain good health?
8. Do you have a mobile phone?
9. Do you access social networks, Facebook or YouTube?
10. Where do you get information from? (television, newspaper, people)
4. Interview guide for managers and staff of NGOs working with ex-prisoners

Oblast_______________________ District_____________________ Village__________________
Gender_____ Age _______ Education__________________________

Managers and staff of NGOs working with ex-prisoners

Interview questions for NGOs working with ex-prisoners will be conducted by partner NGO TB People. They will talk to one or two other NGOs and add their own responses to these questions. The interviews can be with one staff member or with a small group of NGO staff.

Name of interviewer______________ Name of NGO_________________ Date____________
Number of persons in this interview: ______________

Hello, my name is __________, and I represent the USAID Cure Tuberculosis Project. We are conducting this research to study your experience and learn to what extent TB services are available for ex-prisoners with TB. The results of this study will be used to develop actions that would ensure universal and equitable access to quality TB services for different categories of the population. All of the information collected today will be confidential. Your name will not be shared with anyone else. You do not have to participate if you do not want to and are welcome to end our conversation at any time. The interview may take 30 minutes of your time. If you agree to be interviewed, please, sign here.

Signature _____________________________

1. Do most ex-prisoners return to their home city or village, or do they remain in Chui/Bishkek, or go to live in another location that is not their home?

Among those who return home:
2. How well are they received by their families?
3. Are they able to find employment or start a business?
4. Do they face difficulties in accessing social services?
5. Do you think they have access to a mobile phone and do you have a way to get their number if there is a need to contact them about their TB treatment?
6. Can you estimate how many use drugs or alcohol after release from prison?

Among those who stay in Chui or go to another location that is not their home community:
7. Where do they live? With whom?
8. Do you think they have access to a mobile phone and do you have a way to get their number if there is a need to contact them about TB treatment?
9. Are they able to find employment or start a business? What types of work?
10. Do they become registered here? Is this a difficult process for them?
11. Do they face other difficulties in accessing social services?
12. Can you estimate how many use drugs or alcohol after release from prison?
5. DND Individual Interview Ex-prisoners

Oblast________________________ District_________________________ Village_________________________
Gender_______ Age _______ Education____________________________________________________________

DND Questionnaire: TB Complete Treatment for Ex-prisoners

Interviewer: Please read this to the person before passing it for their signature.

Hello, my name is __________, and I represent the USAID Cure Tuberculosis Project. We are conducting this research to study your experience and learn to what extent TB services are available for those in need. The results of this study will be used to develop actions that would ensure universal and equitable access to quality TB services for different categories of the population. All of the information collected today will be confidential. Your name will not be shared with anyone else. You do not have to participate if you do not want to and are welcome to end our conversation at any time. If you choose not to participate, this will not affect your eligibility for receiving health services. The interview will take less than 10 minutes of your time. If you agree to be interviewed, please, sign here.

Signature________________________________________________________

1. Have you completed treatment for TB?
2. What do you see as the advantages of completing treatment for TB?
3. What do you see as the disadvantages of completing treatment for TB?
4. What makes/would make it easier for you to complete treatment for TB?
5. What makes/would make it difficult for you to complete treatment for TB?
6. Who approves or supports you in completing treatment for TB?
7. Who disapproves or does not support you in completing treatment for TB?
6. **FGD guide for external labor migrants**

Oblast_______________________ District_____________________ Village_____________________

Interviewer____________ Note-taker______________

Number of participants __________ Date_________

External Migrants (questions apply to both seasonal and long-term migrants but answers may differ)

*These are people who have been abroad to earn money during the past 3 years, with a stay in the country of employment for at least 3 months.*

*Interviewer will read the informed consent statement to the participants and obtain the list of signatures of those who agree to participate on a separate sheet of paper.*

1. Where have you migrated for work?
   What did you do in those locations?
   How long did you spend in each place?
   How long do you stay in your home between work opportunities abroad?
   (If people have migrated to more than one place, ask them to consider both locations when they answer these questions, if the responses might be different).

2. Why did you decide to work abroad?
   How did you decide where to go?

3. Tell me about your housing situation when you are in your work location.
   How many people do you live with typically?
   How do you know them (did you know them before)?
   How do you find housing?
   What factors help you decide where to live?

4. Of the people that you know in your work location, about how many of them have legal status?
   How difficult is it to migrate with legal status?
   Is it possible for most people to get legal status in another country?

5. What is most important to you in your work location?

6. What is your day like in your work location?
   How many hours do you work?
   How much time do you have to take care of your own personal affairs?
   Do you have the ability (time, means or manager’s permission) to go seek medical care?

7. Among workers abroad, how do people decide how much money to send home and how much you can spend on your needs?

8. How do you feel about spending money on your medical treatment in your location of work?

9. What opportunities for medical services do you have access to in your location of work?
   Is it easy or hard to find treatment? Why?

10. How are migrant workers abroad treated when they seek medical services?

11. Do you know about people in your work location who have or had TB?
   Were they diagnosed before migrating or in the work location?
   Were they able to find treatment?
   If so, how?
12. What do you think would happen if an employer found out that an employee has TB?
   How would the person’s colleagues, or housemates react?

13. How often were you able to communicate with your family in Kyrgyzstan?
   How do you communicate (phone, SMS, social media)?
   Do you talk about your and your family’s health?
   What makes communication with your family difficult?

14. Is communication with people in Kyrgyzstan expensive?
   Are you able to receive SMS messages for free from Kyrgyzstan in your location of work?

15. If a family member back home (such as a wife or child) had a serious illness with lots of coughing, how would you react?
   What would you tell your family to do?
   Could you ask anyone else in your community to help?
   What would you want them to do?

16. Imagine that you learned you had TB in your work location – how do you think your family would react?
   What would they want you to do?
   a. Probe – Would they prefer you to come back to Kyrgyzstan or stay to work? Why?
7. FGD Guide for families of external migrants

Oblast_______________________ District____________________ Village____________________
Interviewer__________________ Note-taker__________________
Number of participants_______________ Date____________

Family members of external migrants

Interviewer will read the informed consent statement to the participants and obtain the list of signatures of those who agree to participate on a separate sheet of paper.

1. Who in your family has migrated for work?
   Where has your family member migrated for work?
   What did s/he do in those locations?
   How long did s/he spend in each place?
   (If people have migrated to more than one place, ask them to consider both locations when they answer these questions, if the responses might be different).
2. Why did your family member decide to work abroad?
   How did s/he decide where to go?
3. Tell me what you know about your family member’s housing situation in the work location.
   How many people does s/he live with?
   How does s/he know them (from your home location or are they strangers)?
   How does s/he find housing? What factors help him/her decide where to live?
4. Of the people that you know who work abroad, about how many of them have legal status?
   How difficult is it to migrate with legal status?
   Is it possible for most people to get legal status in another country?
5. What do you think is most important to your family member when s/he is in his/her work location?
6. What does the family plan to do with the money earned and sent back to Kyrgyzstan?
   What do families typically plan to do with the money that is earned by family members and sent back to Kyrgyzstan?
   What would happen if the family did not receive this money?
7. What is your family member’s day like in the work location – how many hours does s/he work?
   How much time does s/he have to take care of their own personal affairs?
   Does s/he have the ability (time, means or manager’s permission) to go seek medical care?
8. Among workers abroad, how do people decide how much money to send home and how much the family member can spend on his/her needs?
9. If the family member needed to pay for medical treatment, how would the family react to receiving less money in remittances?
10. What opportunities for medical services does the family member have access to in the work location? Is it easy or hard to find treatment? Why?
11. What do you know about how migrant workers abroad are treated when they seek medical services?
12. Do you know about people in the family member’s work location who have had TB?
    Were they diagnosed before migrating or in the work location?
    Were they able to find treatment, and if so, how?
13. What do you think would happen if people in the work location knew that someone had TB (such as the employer, colleagues, housemates)?
14. How often were you able to communicate with your family member from Kyrgyzstan?
   How do you communicate (phone, SMS, social media)?
   Do you talk about your family’s health?
   What makes communication with your family difficult?
15. Is communication (phone calls, SMS etc) in Kyrgyzstan expensive?
16. If your family member abroad had a serious illness with lots of coughing, how would you react?
   What would you tell him or her to do?
   Could you ask anyone else to help?
   What would you want them to do?
17. If your family member abroad were diagnosed with TB, what would be most important: for your family member to return to Kyrgyzstan for treatment, or for him/her to continue working abroad? Why?
8. FGD Guide for Internal Migrants

Oblast_______________________ District_____________________ Village__________________
Interviewer____________ Note-taker____________
Number of participants ___________________ Date___________

New Internal Migrants (People who have moved to Bishkek city and Chui oblast from other parts of Kyrgyzstan) within the past 3 years and live in the new settlements (novostroiki)

Interviewer will read the informed consent statement to the participants and obtain the list of signatures of those who agree to participate on a separate sheet of paper.

1. Where have you migrated from? Why did you decide to come to this area? How did you decide where to go?
2. Tell me about your housing situation when you are in your work location. How many people do you live with typically? How do you find housing? What factors help you decide where to live?
3. Are many people who live near you registered as an oblast/rayon resident? How difficult is it to update your registration status? What benefits can people access when they are a registered resident?
4. What is most important to you in your life here?
5. What is your day like – how many hours do you work? How much time do you have to take care of your own personal affairs? Do you have the ability (time, means or permission) to go seek medical care?
6. Do you send money home to your family? (If yes,) How do people who send remittances home decide how much money to send home and how much you can spend on your needs?
7. How do you feel about spending money on your medical treatment in your location of work?
8. What opportunities for medical services do you have access to where you live? Is it easy or hard to find treatment? Why?
9. How are new residents from other oblasts of Kyrgyzstan (or residents from new settlements) treated when they seek medical services?
10. Do you know about people in your community who have or had TB? Where were they diagnosed? Did they receive treatment, and if so, how?
11. What do you think would happen if people in your community knew about someone who had TB? How would they react to that person?
12. How often were you able to communicate with your family? How do you communicate (phone, SMS, social media)? Do you talk about your and your family’s health? What makes communication with your family difficult to do?
13. If a family member back home (such as a wife or child) had a serious illness with lots of coughing, how would you react? What would you tell your family to do? Could you ask anyone else in your community to help? What would you want them to do?
9. FGD guide with Health care workers

Oblast_______________________ District____________________ Village________________
Interviewer____________ Note-taker_____________
Number of participants ____________________ Date___________

List the position of the HCW(s) interviewed (doctors, nurses, etc.)

Health care workers

Formative research with health care workers will be in the form of either a focus group discussion or, if unable to convene a group, these questions may be used for in-depth interviews. Participants will include both HCWs who treat patients with diagnosed TB and HCWs whose job responsibilities include screening for TB or, at a minimum, referring patients for screening. Formative research on this group (or multiple individuals) will be conducted in Chui oblast with at least half in Bishkek. Interviewer will read the informed consent statement to the participants and obtain the list of signatures of those who agree to participate on a separate sheet of paper.

Perceptions and attitudes about TB

1. What types of patients do you typically see?
   About how many of them are TB patients?
   How has this changed over the time you have been working?

2. What do healthcare workers think about TB, how has this changed over time (e.g., experience working with TB patients)?

3. What do you think people in the community think or feel about TB?

4. How would your colleagues describe TB patients?
   How are TB patients different from other types of patients?
   What kind of people get TB?

5. What kinds of behaviors or risk factors make people susceptible to contracting TB?

6. Do you think any of your work colleagues hold personal concerns about TB patients?
   What are those concerns, and why do you think they have them?

Workplace

7. How are you supported at work, what is your relationship with colleagues, senior staff, other cadres of health workers, support staff?

8. What do your family, friends, and colleagues think about the fact that you work with TB patients?

9. How do HCWs perceive risk of TB infection, what countermeasures (e.g., infection control practices) do HCWs take and how do they feel about these measures?
TB service delivery

10. What TB specific activities do you administer, what types of health care tasks are you directly involved in (e.g., testing, counseling, contact tracing, treatment initiation, treatment observation or monitoring, adherence support, outreach)?

11. How do you feeling about doing these activities, what challenges have you faced and how did you deal with them, ask for examples of specific interactions with patients?

12. Did you ever have concerns about working with TB patients? What were those concerns, and have they changed over time?

13. What do you think are the most common problems or needs of TB patients themselves? What help do they ask of healthcare workers? How do healthcare workers respond?

14. How else do you think your TB patients can be supported?

15. How else can you be supported in accomplishing your TB-related duties, what would be your preference?
10. FGD Women of general population

Oblast_______________________ District ________________________ Village__________________
Interviewer____________ Note-taker ________________
Number of participants ____________________ Date____________

Women (General population)

Interviewer will read the informed consent statement to the women and obtain the list of signatures of those who agree to participate on a separate sheet of paper.

1. What is tuberculosis? What are the symptoms?

2. How is it transmitted?
   Do not prompt immediately!
   Probe: What kind of people get TB? (living conditions, social status...)

3. What do you know about treatment for this disease?
   Do not prompt immediately!
   Probe: Do they know it is curable?

4. What will happen to someone who becomes sick with tuberculosis if they don’t get treatment?

5. If someone is diagnosed with tuberculosis, how does the family react?
   Do not prompt immediately!
   Probe: Are there families who don’t want to tell anyone when a family member is diagnosed with TB?
   Probe: If so, why do you think they don’t want to tell anyone?

6. What is the worst thing that would happen to this family if they told people about the TB?
   Probe – shunned, job loss, marriage prospects, mistreatment by health care providers ...

7. Do you know families who told about the TB and these things did happen? Or did not happen?
   Do not prompt immediately!
   Probe: ask for specific cases

8. Do you know women who told their family they had a TB diagnosis and the family did not support them?
   Do not prompt immediately!
   Probe: ask for specific cases

9. Why do you think people are so concerned or upset about TB? Compared to other diseases?

10. What do you think neighbors and other community people can do to help someone who has a TB diagnosis?
    Do not prompt immediately!
    Probe for attitudes and actions.
11. FGD Guide for Men of General Population

Oblast_______________________ District_______________________ Village_______________________
Interviewer____________ Note-taker______________
Number of participants____________________Date______________

**Men (general population)**

*Interviewer will read the informed consent statement to the participants and obtain the list of signatures of those who agree to participate on a separate sheet of paper.*

1. What is tuberculosis? What are the symptoms?

2. How is it transmitted?

Do not prompt immediately!

Probe: What kind of people get TB? (living conditions, social status...)

3. What do you know about treatment for this disease?

4. What will happen to someone who becomes sick with tuberculosis if they don’t get treatment?

5. If someone is diagnosed with tuberculosis, how does the family react?

Do not prompt immediately!

Probe: Are there families who don’t want to tell anyone when a family member is diagnosed with TB?

Probe: If so, why do you think they don’t want to tell anyone?

6. What is most important to you in your life here?

7. What is your day like – how many hours do you work? How much time do you have to take care of your own personal affairs? Do you have the ability (time, means or permission) to go seek medical care?

8. What opportunities for medical services do you have access to where you live? Is it easy or hard to find treatment? Why?

9. Do you know about people in your community who have or had TB? Were they able to find treatment, and if so, how?

Do not prompt immediately!

Probe: attitude and actions
12. DND individual interview on stigma (women)

Oblast_______________________ District_______________________ Village_______________________
Gender_______ Age _______ Education________________________________________________________

Women on stigma (general population)
Doer/Non-doer questionnaire (DND)

Interviewer: Please read this to the person before passing it for their signature.

Hello, my name is __________, and I represent the USAID Cure Tuberculosis Project. We are conducting this research to study your experience and learn to what extent TB services are available for those in need. The results of this study will be used to develop actions that would ensure universal and equitable access to quality TB services for different categories of the population. All of the information collected today will be confidential. Your name will not be shared with anyone else. You do not have to participate if you do not want to and are welcome to end our conversation at any time. If you choose not to participate, this will not affect your eligibility for receiving health services. The interview will take less than 10 minutes of your time. If you agree to be interviewed, please, sign here.

Signature______________________________________________________

1. Have you told anyone outside the family that your family member has TB?
2. What do you see as the advantages (good/positive) of telling people outside the family that someone in your family has TB?
3. What do you see as the disadvantages (bad/negative) of telling people outside the family that someone in your family has TB?
4. What makes/would make it easier for you to tell people outside the family that someone in your family has TB?
5. What makes/would make it difficult for you to tell people outside the family that someone in your family has TB?
6. Who approves or supports you in telling people outside the family that someone in your family has TB?
7. Who disapproves or does not support you in telling people outside the family that someone in your family has TB?
13. DND individual interview: TB Testing

Oblast_______________________ District_____________________ Village________________
Gender_______ Age _______ Education____________________________________________

TB Testing
Doer/Non-doer Questionnaire

Interviewer: Please read this to the person before passing it for their signature.

Hello, my name is __________, and I represent the USAID Cure Tuberculosis Project. We are conducting this research to study your experience and learn to what extent TB services are available for those in need. The results of this study will be used to develop actions that would ensure universal and equitable access to quality TB services for different categories of population. All of the information collected today will be confidential. Your name will not be shared with anyone else. You do not have to participate if you do not want to and are welcome to end our conversation at any time. If you choose not to participate, this will not affect your eligibility for receiving health services. The interview will take less than 10 minutes of your time. If you agree to be interviewed, please, sign here.

Signature________________________

1. Have you sought testing for TB?
2. What do you see as the advantages (good) of being tested for TB?
3. What do you see as the disadvantages (bad) of being tested for TB?
4. What makes/would make it easier for you to be tested for TB?
5. What makes/would make it difficult for you to be tested for TB?
6. Who approves or supports you in being tested for TB?
7. Who disapproves or does not support you in being tested for TB?
Starting TB treatment

Oblast_______________________ District_____________________ Village__________________
Gender_______ Age _______ Education____________________________________________

Starting Treatment
Doer/Non-doer Questionnaire

Interviewer: Please read this to the person before passing it for their signature.

Hello, my name is __________, and I represent the USAID Cure Tuberculosis Project. We are conducting this research to study your experience and learn to what extent TB services are available for those in need. The results of this study will be used to develop actions that would ensure universal and equitable access to quality TB services for different categories of population. All of the information collected today will be confidential. Your name will not be shared with anyone else. You do not have to participate if you do not want to and are welcome to end our conversation at any time. If you choose not to participate, this will not affect your eligibility for receiving health services. The interview will take less than 10 minutes of your time. If you agree to be interviewed, please, sign here.

Signature_________________________________________________

1. Have you started treatment for TB?
2. What do you see as the advantages (good) of starting treatment for TB?
3. What do you see as the disadvantages (bad) of starting treatment for TB?
4. What makes/would make it easier for you to start treatment for TB?
5. What makes/would make it difficult for you to start treatment for TB?
6. Who approves or supports you in starting treatment for TB?
7. Who disapproves or does not support you in starting treatment for TB? Why?
15. DND individual interview: Complete TB Treatment

Oblast_______________________ District_____________________ Village__________________
Gender_______ Age _______ Education____________________________________________

TB Complete Treatment
Doer/Non-doer Questionnaire

Interviewer: Please read this to the person before passing it for their signature.

Hello, my name is __________, and I represent the USAID Cure Tuberculosis Project. We are conducting this research to study your experience and learn to what extent TB services are available for those in need. The results of this study will be used to develop actions that would ensure universal and equitable access to quality TB services for different categories of population. All of the information collected today will be confidential. Your name will not be shared with anyone else. You do not have to participate if you do not want to and are welcome to end our conversation at any time. If you choose not to participate, this will not affect your eligibility for receiving health services. The interview will take less than 10 minutes of your time. If you agree to be interviewed, please, sign here.

Signature_________________________________________________

1. Have you completed treatment for TB?
2. What do you see as the advantages (good) of completing treatment for TB?
3. What do you see as the disadvantages (bad) of completing treatment for TB?
4. What makes/would make it easier for you to complete treatment for TB?
5. What makes/would make it difficult for you to complete treatment for TB?
6. Who approves or supports you in completing treatment for TB?
7. Who disapproves or does not support you in completing treatment for TB?
Annex 5. Doer/Non-Doer Screening Questions and Inclusion/Exclusion Criteria

Screening questions for doer/non-doer questionnaires

Do you have TB?
Depending on this answer (if not clear), ask about testing – did they have symptoms and go for testing?

Are you on treatment for TB?

Have you completed treatment?
If yes, when did you complete treatment? How long were you on treatment for (record number of months total)?
If no, determine if they are still on treatment or if they have defaulted?

When did you start treatment?

Do you know which form of TB you have/had (regular, MDR, XDR)?
If the patient does not know, ask related questions like whether or not they were hospitalized, length of treatment, type of regimen with many drugs or injections etc.

Process: Ask these questions only verbally, assign the participant to the most appropriate category based on the inclusion/exclusion criteria below, read them the informed consent form and ask them to sign and begin the appropriate questionnaire. When beginning the interview, note some of the information obtained above from the screening questions at the top of the questionnaire (number of months on treatment, form of TB)

General note: for the complete treatment questionnaires, the questions will relate to the very long process of having stayed on treatment for many months in order to achieve treatment completion. In contrast, the questionnaires for Start treatment and Testing relate to the specific point in time when the person decided to seek testing after a certain time of experiencing symptoms, or decided to start treatment after a certain time of being diagnosed. Therefore, please make sure the questions for those interviews relate to that point in time (in the past) rather than the current realities of being on treatment for those on treatment, for example. We are interested in the specific behavior of seeking testing and starting treatment for those, rather than staying on treatment (for treatment completion).
### Inclusion/Exclusion criteria

<table>
<thead>
<tr>
<th></th>
<th>Complete treatment</th>
<th>Start treatment</th>
<th>Testing</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Doer</td>
<td>Non-doer</td>
<td>Doer</td>
</tr>
<tr>
<td><strong>Inclusion criteria</strong></td>
<td>- Has completed treatment (received final results and treatment completion confirmed by a doctor)</td>
<td>- Decided to stop treatment – this includes default and lost-to-follow-up (ideal scenario)</td>
<td>- Had symptoms of TB</td>
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<tr>
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<td></td>
<td>- Decided to interrupt treatment for a significant period of time (e.g. 2 months, not just a few days)</td>
<td>- Was diagnosed with TB</td>
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<td></td>
<td>(use this scenario if we cannot recruit enough non-doers)</td>
<td>- Currently on treatment for TB</td>
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<td></td>
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<td>- Had symptoms of TB</td>
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<td></td>
<td></td>
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<td>- Did not decide to start treatment</td>
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<tr>
<td><strong>Exclusion criteria</strong></td>
<td>DO NOT include patients who have not completed treatment because they are currently on treatment (these belong in Start treatment/Doer)</td>
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<tr>
<td><strong>Comments</strong></td>
<td>Based on screening questions, determine how long they have been on treatment and how much longer they have to go</td>
<td>Note: does not matter if they tested negative for TB (the important part is going for testing)</td>
<td>Note: they may still be sick, or this may have been an event in the past</td>
</tr>
</tbody>
</table>
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5 National TB Program 2018 Annual Report

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7 NTP 2018 Annual Report

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9 National Statistical Committee 2018.


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