



# ASSESSMENT OF CRG BARRIERS FOR TB HIGH-RISK GROUPS IN GEORGIA



Tbilisi, 2020

**Project:** “Assessment of CRG barriers for TB high-risk groups in Georgia” within the framework of multi-country program “Advancing People-Centered Quality TB Care - From the New Model of Care Towards Improving DR-TB Early Detection and Treatment Outcomes” (TB-REP 2.0).

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## Abbreviations

<b>CRG</b>	Community, Rights , Gender
<b>CSO</b>	Civil Society Organization
<b>DOT</b>	Directly observed therapy
<b>GF</b>	Global Fund to Fight AIDS, Tuberculosis and Malaria
<b>HIV</b>	Human Immunodeficiency Virus
<b>IDP</b>	Internally displaced person
<b>KAP</b>	Knowledge, Attitudes, Practices
<b>LGBT</b>	Lesbian, gay, bisexual and transgender
<b>MDR TB</b>	Multidrug-resistant
<b>MOH</b>	Ministry of Health
<b>NCDC</b>	National Center for Disease Control and Public Health
<b>NCTBLD</b>	National Center for Tuberculosis and Lung Disease
<b>NGO</b>	Non-governmental organization
<b>NSP</b>	National Strategic Plan
<b>NTP</b>	The National Tuberculosis Control Programme
<b>PHR</b>	Populations at high risk
<b>PWID</b>	People who inject drugs
<b>PWTB</b>	People with Tuberculosis
<b>SMT</b>	Substitution maintenance therapy
<b>TB</b>	Tuberculosis
<b>WHO</b>	World Health Organization
<b>XDR TB</b>	Extensively drug-resistant TB



## Executive Summary

This assessment of Communities, Rights and Gender (CRG) in Georgia has been carried out by “New Vector” as part of “Advancing people-centered quality Tuberculosis care – from the new model of care towards improving DR-TB early detection and treatment outcomes” (TB-REP 2.0) project, funded by the Global Fund. The report was developed based on a desk review and qualitative data collected through interviews and focus group discussions. All instruments have been approved by the Bioethics Council of the National Center for Disease Control and Public Health. The assessment methods included two multi-stakeholders meetings to set the assessment priorities and later to validate the results and develop a plan of actions to address barriers. In addition, a core working group was established to provide close guidance to the implementation of the CRG assessment.

Three key populations: (ex-)prisoners, internally displaced persons (IDP) and people who use drugs (PWUD) were identified with the help of multi-stakeholders as most at-risk and the barriers faced by these groups were further investigated by the assessment. The barriers identified in the assessment were categorized according to TB Journey, which include seven stages from recognizing TB symptoms on to diagnosis, treatment, adherence support and post-treatment follow up. The assessment also specified barriers in the areas of gender, stigma and human rights. The most important barriers are highlighted below:

**Gender:** in Georgia there is more TB diagnosed in men than in women. Interviews showed women are more apprehensive of TB, they may delay engaging in treatment because of family responsibilities, financial difficulties (especially in rural women) or unavailability of child care, they are less likely than men to be supported by family members. Women’s awareness about TB is lower than men’s. However, once on treatment women’s outcomes, including adherence are better than men’s. Men’s reason to delay diagnosis and treatment was fear of losing paid jobs. Respondents, especially underlined the psychological toll of TB and its consequences (inability to work) on men and the related need for support. LGBTQI persons reported having fears of being mistreated by health care staff.

**Stigma:** is a big barrier at all stages of TB Journey that impeded access to TB diagnosis and treatment across the gender spectrum, it impacts key populations and people with TB who do not belong to any specific at-risk or vulnerable groups. Our assessment found that stigma and fear of discrimination stopped some of the respondents from informing their families and employers about the fact that they had TB. Collecting TB drugs or delivery of TB drugs by DOT nurses were not always suitable options for TB patients who feared being identified as such in the community.

**Human rights:** according to some respondents non-TB medical facilities carry out paid tests before referring for free TB treatment. Various state jobs may ask the job applicant to share the TB treatment history which is not in line with labor legislation. When a person is socially vulnerable and receives an incentive for treatment, the state calculated the incentive as additional income and this may result in a cancellation of social assistance.

Key populations: PWUDs reported fear of legal persecution as a barrier to visiting health facilities; for IDPs the remoteness of health facilities was reported as a substantial barriers; IDPs especially avoid sharing information about their diagnosis to prevent being stigmatized by their family or the community as they live in a densely populated areas. A case of double stigma is common regarding TB diagnosis and being a PWID or an ex-prisoner.

The key recommendations are summarized as follows:

1. Filling informational gaps by providing information about TB in a way that is gender-sensitive, key population-sensitive and based on respecting human right.
2. Advocating for the rights of people with TB (PWTB), including rights to work, non-discrimination and privacy.
3. Advocate for PWTB to not lose social support, provided by the government as a result of receiving TB adherence incentive to support their treatment.
4. Investing in TB program capacity building especially at the periphery, including facilities that cater to IDPs.
5. Advocating to allow CSOs, including key populations' and LGBTQI CSOs, to provide one window principle services that include TB.
6. Continuing advocacy for outpatient based treatment and people-centered model of care to differentiate services to make them acceptable for PWTB depending on their unique situations.
7. Increasing patient adherence by delivering gender-sensitive psychological support(peer-to-peer and/or by social workers) to the patients and their family members.



## Introduction

“Advancing people-centered quality Tuberculosis care – from the new model of care towards improving DR-TB early detection and treatment outcomes” (TB-REP 2.0) is funded by the Global Fund through the principal recipient PAS Center for Health Policy and Studies. The project is implemented in 11 countries in Eastern Europe and Central Asia (Armenia, Azerbaijan, Bela-rus, Georgia, Kazakhstan, Kyrgyzstan, Moldova, Tajikistan, Turkmenistan, Ukraine, Uzbekistan). The project envisages the involvement of non-governmental organizations in the treatment of tuberculosis (TB), people-centered care, strengthening the health care system and ensuring sustainability

Under the umbrella of the TB REP 2.0, PAS Center for Health Policy and Studies has announced a small grant to conduct CRG (Community, Rights, Gender) assessments in several high-priority countries to capture barriers in access to TB diagnosis and treatment, especially among key and vulnerable populations most affected by TB. ;

Non-governmental organization «New Vector» received a grant in Georgia to conduct the assessment. «New Vector» is the first community-based organization of people who use drugs (PWUD) in Georgia which has been operating since 2006. The mission of «New Vector» is to promote the recovery of drug users, including HIV-positive people with hepatitis B and C and tuberculosis, and to reintegrate them into society. Accordingly, the organization provides harm reduction services conducts advocacy and participates in various decision-making at local and national levels.

## Assessment Objectives

### Project goal:

Assess the barriers on community, rights, gender and stigma dimensions of TB response for strengthening strategies in finding people who are missed by health system.

### Project objectives:

1. Engage decision makers and relevant stakeholders in the process of CRG assessment on TB in Georgia
2. Identify and address the barriers related to community, rights, gender and stigma that people with TB have.
3. Develop concrete recommendations and contribute to the action plan, for eliminating outlined barriers.

As a result of the assessment 40 barriers were identified, of which multi-stakeholders prioritized 25 and validated and gave additional recommendations about how to remove them. Provided recommendations aim to address community, rights, gender and general barriers of people with TB (PWTB). It needs to be mentioned, that most of the barriers and recommendations for general TB population and the three prioritized key populations (PWID, IDP and persons with history of imprisonment) were similar. Where applicable, information specific to key populations is outlined among the barriers and recommendation in Table 1.

**TABLE 1. BARRIERS, RECOMMENDATIONS AND ACTIONS**

Barriers, prioritized by multi-stakeholders	Recommendations, validated by multi-stakeholders	Proposed actions
<ul style="list-style-type: none"> <li>• I- <i>Key Barriers to Recognizing Symptoms</i></li> </ul>		
<ul style="list-style-type: none"> <li>• Lack of knowledge/ lack of info about symptoms (including KPs and gender)</li> <li>• People with HIV do not have information about TB regardless that there is a high risk of coinfection</li> <li>• Women de-prioritize seeking care because of other obligations</li> </ul>	<ul style="list-style-type: none"> <li>• Awareness raising and knowledge/ information campaign designed in a gender transformative way providing up to date info about where to turn for a medical check-up (general) and TB symptoms recognition;</li> <li>• Develop mechanisms for women helping not to “deprioritize seeking care” because of family obligations;</li> <li>• Address the barriers during the information campaign world TB day;</li> </ul>	<ul style="list-style-type: none"> <li>• Develop a short gender-transformative TB awareness video, covering the TB Journey, the need for community/ family support, map of testing facilities and providing TB Center hotline number. ( an infographic video has been developed by New Vector under TB REP 2.0)</li> <li>• Jointly develop at least one event with organizations, working with TB affected communities (e.g. ethnic minorities), and their constituencies, including women’s organizations, on the World TB Day, including low-threshold interactive and culturally acceptable activities in a location close to the affected communities. Including CSOs Tanadgoma, GHRN, TB People, Phoenix, New Vector.</li> <li>• E-learning platform - Network TB People is working on development of an e-learning platform, tentatively called TEACH ME TB, (partnering with PAS Center within the framework of the TB-REP 2.0 project) which will provide interactive, evidence-based training on all topics related to TB prevention, diagnosis, treatment, care and support, human rights, integrated people-centered care, advocacy, communication, awareness raising, service provision, etc. Importantly, courses will be delivered in ways easily accessible for all target groups, combining video lectures, reading materials and practical exercises. This platform could be promoted to be used as a tool to raise awareness among women.</li> </ul>

## II- Key Barriers to Seeking Care

- |   |   |  |
|---|---|--|
| <ul style="list-style-type: none"> <li>• Lack of information about where to turn for a medical check-up; (KP-specific and gender-sensitive information)</li> <li>• Financial problems of women (especially in rural areas) and less power over family budget, lead to complications in covering payments during treatment process.</li> <li>• Women lack assistance and support during checkups (women make the visits alone, men are more likely to be supported by family)</li> <li>• LGBTQI patients have fears of being treated badly by medical institutions and service providers;</li> <li>• A person may delay seeking care after being referred by the family doctor for TB diagnosis because of remoteness (mostly in rural areas, including IDPs).</li> <li>• Drug users outside the methadone program are afraid to visit the health system facility because of the suspicion that they may be exposed (facing legislation issues)</li> </ul> | <ul style="list-style-type: none"> <li>• Address the needs of communities (people who use drugs (PWUD)/ LGBTQI) who have TB in the first place; create the one window principle.</li> <li>• To have more campaigns to raise awareness, starting from the educational system.</li> </ul> | <ul style="list-style-type: none"> <li>• Organize a round table including representatives of NCDC, NTP, Ministry of Health, CSOs (Tanadgoma, GHRN, TB People, Phoenix, New Vector). Advocate for NTP decentralization, allowing CSOs, including KP and LGBTQI CSOs, to provide one window principle services.</li> <li>• With the cooperation of Ministry of Education, medical profile universities and CSOs (Tanadgoma, GHRN, TB People, Phoenix, New Vector), introduce the element of gender sensitivity into the curriculum.</li> <li>• With the cooperation of Ministry of Education and CSOs (Tanadgoma, GHRN, TB People, Phoenix, New Vector) introduce information about TB as a part of the secondary school curriculum (risks, prevention, symptoms, diagnosis, treatment, care and stigma).</li> </ul> |
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- III- Key Barriers to Getting an Accurate Diagnosis		
<ul style="list-style-type: none"> <li>• Because in women TB is suspected less often than in men – this may lead to late diagnosis.</li> <li>• When there is suspicion on TB, in some cases family doctors test the patient in the facility they work and do not refer them to the TB facility straight away for the free testing. That is done in order to maximize profits for the non-TB facility.</li> </ul>	<ul style="list-style-type: none"> <li>• Awareness raising and knowledge/ information campaign designed especially for women providing up to-date info about where to turn for a medical check-up (general) and TB symptoms recognition;</li> <li>• Design and perform special diagnostic toolkits for family doctors for referring persons to TB center;</li> <li>• Increase “family support” educational campaigning targeting women role enhancement as a healthy member of family and community in a whole; targeted campaign ethnic groups/women;</li> <li>• TB awareness training for the staff of PLWHIV NGOs;</li> </ul>	<ul style="list-style-type: none"> <li>• Assess existing knowledge, and capacity building needs of HIV CSOs (Tanadgoma, GHRN, TB People, Phoenix, New Vector) in the area of TB: to identify gaps and most effective intervention(s): e.g. short-training, referral to an existing online resource, development of a special/ specific (online) resource or materials. Subsequently advocate for the inclusion of the identified intervention into the ongoing Global Fund-supported activities.</li> </ul>

• **IV- Key Barriers to Beginning Treatment**

<ul style="list-style-type: none"> <li>• Fear that “women who had TB might not get married”;</li> <li>• Women with TB may face a divorce from their husbands on the grounds of having TB and stop having access to their children; (with the force from the partner, the family members)</li> <li>• Person diagnosed with TB are afraid their job positions will be affected by the diagnosis. Considering this, they prefer to not engage into the treatment with the fear, that others might know; (concerns IDPs as they live in a densely populated areas)</li> <li>• The patients avoid sharing information about their diagnosis to prevent being stigmatized by their family or the community; (concerns IDPs as they live in a densely populated areas)</li> <li>• Various state jobs may require the TB treatment history with the job application. This is not demanded by law, the requirement is set by the employer’s will.</li> </ul>	<ul style="list-style-type: none"> <li>• Address the barriers during the information campaign world TB day;</li> <li>• The national program to consider strengthening the diagnostic capacity of region dispensers;</li> <li>• Strengthening the collaboration between the system and civil organizations to improve health diagnosis;</li> <li>• Advocate for the outpatient based treatment;</li> <li>• TB service collaborates with NGOs/peer educators to organize an outreach work;</li> </ul>	<ul style="list-style-type: none"> <li>• The Ministry of Health must work on strengthening the diagnostic capacity of region dispensers with the NTP.</li> <li>• Ministry of Health and NTP must continue to advocate for outpatient based treatment and people-centered model of care to differentiate services to make them acceptable for PWTB depending on their unique situations (e.g. IDP).</li> <li>• Advocate to change job application requirements in state jobs allowing the employer to ask the employee if they have TB past experience.</li> </ul>
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• **V- Key Barriers to Getting Treatment Adherence Support**

<ul style="list-style-type: none"> <li>• Delayed treatment because of family obligations including having to care for children;</li> <li>• Society has the myths that the medicine used is not tested yet and is being tested on those persons;</li> </ul>	<ul style="list-style-type: none"> <li>• Awareness raising and knowledge/information campaign designed especially for women providing up to -date info about where to turn for a medical check-up (general) and TB symptoms recognition;</li> <li>• Address the barriers during the information campaign world TB day;</li> <li>• Increase “family support” educational campaigning targeting women role enhancement as a healthy member of family and community in a whole; targeted campaign ethnic groups/women;</li> <li>• Making treatment supporters more aware of the special mental health support needs of men;</li> <li>• Educational work towards “Not to Stop the Treatment” because the physical condition improves – case provision, illustration lecturing etc. treatment supporters;</li> </ul>	<ul style="list-style-type: none"> <li>• NTP and CSOs (Tanadgoma, GHRN, TB People, Phoenix, New Vector) must work on a joint adherence support plan, delivering psychological, peer-to-peer, social work services to the patients and their family members. Psychological services must be gender sensitive (for men, women, trans people)</li> <li>• Arrange a round table with the purpose to advocate for increasing the number of social procurement tenders by the government for health and (if applicable) particularly TB.</li> </ul>
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<ul style="list-style-type: none"> <li>VI- <i>Key Barriers to Completing Treatment</i></li> </ul>		
<ul style="list-style-type: none"> <li>When a person is socially vulnerable and receives an incentive for treatment, the state allocates that amount to a source as an income and declines social assistance;</li> <li>Some of the patient TB Facilities have infrastructural problems which leads patients to leave the treatment;</li> <li>Patients would refuse the DOT nurse bringing medications to their homes because someone can see them;</li> <li>Society might refer to TB Patient as someone who is a drug user or a former prisoner (this is the case of double stigma);</li> <li>Stopping the treatment because the physical condition improves, before the treatment is completed;</li> <li>Men reported feeling of being unnecessary, suicidal thoughts – and stopping the treatment;</li> <li>PWUDs may need longer time to see their health improvement, this may become the reason for them to interrupt the treatment;</li> </ul>	<ul style="list-style-type: none"> <li>Include the family members in the work with the psychologist;</li> <li>TB awareness training for the staff of PLWHIV NGOs;</li> <li>Advocate for the benefit not to be counted as the overall household income;</li> <li>TB service collaborates with NGOs/peer educators to organize an outreach work;</li> <li><i>In schools/kindergartens the testing to be confidential .</i></li> </ul>	<p>Organize a round table for the rights and confidentiality issues:</p> <ul style="list-style-type: none"> <li>NTP to organize high level meeting to initiate that the program incentives do not count as an income. Involve Ministry of health, Social Service Agency, Revenue Service, corresponding bank.</li> <li>The testing in schools and kindergartens to be carried out while guaranteeing confidentiality by health ministerial, by TB facilities</li> </ul>
<ul style="list-style-type: none"> <li>VII- <i>Key Barriers to Getting Post-Treatment Follow-up Services</i></li> </ul>		
<ul style="list-style-type: none"> <li>Lack of patients' understanding of the need for follow up after completing TB treatment; former patients do not want to be reminded of this period.</li> </ul>	<ul style="list-style-type: none"> <li>Nurses need to inform the patients about the post treatment check-ups during the treatment.</li> <li>Implementing Promotional and concernment actions to get involved into Post-Treatment Follow-up Services</li> </ul>	<ul style="list-style-type: none"> <li>Informational campaign to raise awareness on the need of post-treatment check-up (need of post-treatment follow up check-up has been covered by the infographic video developed by New Vector under TB REP 2.0)</li> <li>NTP must continue to inform people with TB about the need of post treatment check-ups.</li> </ul>



# Assessment Methods

## 1. Core Group

That there was a Core Group created on the date of September 5, 2019. With the purpose of overseeing the assessment, give feedback, facilitate access to affected population etc).

The core group members were chosen based on their experience in the field of TB. Mostly the members were representatives of the NGOs that have worked with TB patients through various projects and had been interacting with the patients on the project level. Apart from delivering medical, social and psychological services to TB patients, the representatives have also participated in the advocacy processes to ensure persons affected with TB with needed services and rights. National Center for Tuberculosis and Lung Disease was also represented within the core group. Total of 7 members were engaged in the core group work.

The first introductory meeting On September 5, 2019 was held face-to-face, where the project and project staff were introduced. After this process the coresspondance was made online. Core group members were consulted on various subjects including the protocol and tools, multi-stakeholder guests, experts to involve in the expert interviews and the report.

## 2. Multi-stakeholder meetings

The objectives of the multi-stakeholder meeting were:

- to give feedback to the preliminary desk review findings, give recommendations and endorse the data collection tools, reach a consensus regarding the priority key populations for the assessment, present, validate and prioritize the barriers related to community, rights, gender and stigma
- outline recommendations to remove the prioritized barriers
- draft actions for inclusion into the National TB Strategy, the Global Fund grant

**Participants Composition:** Multi-stakeholders included relevant governmental and non-governmental organizations, representatives of the service provider structures, persons affected by TB.

A prioritization multi-stakeholder workshop took place on October 24<sup>th</sup>, 2019 and a validation workshop on February 27<sup>th</sup>, 2020.

## 3. Desk Review

Desk review was developed and edited throughout the whole assessment period. Three staff members worked on the document: a research consultant, a legal consultant and a gender consultant. The information was received from various sources including the national plans, published research papers, reports, statistics received from the relevant structures (TB center, NCDC, penitentiary system, etc.) full list of sources in in Annex.

According to the desk review and State standard for clinical condition management (2015 NCDC) the following TB high-risk groups were identified for discussion:

1. Family and other contacts of a MTB (+) TB patient;
2. Persons in detention prison and released from prison;
3. People with HIV/AIDS (PLHIV);
4. People who use drugs (PWUD), tobacco and alcohol users;
5. Diabetics;
6. Patients with stomach and duodenal ulcer;
7. Patients with mental problems;
8. Patients on radiation therapy, steroid, cytostatic treatment;
9. Persons with low body mass;
10. Patients after organ transplantation;
11. Hemodialysis patients;
12. Persons with TB in the past;
13. Vulnerable people:
  - a. Internally Displaced Persons (IDP);
  - b. Persons living in congregate settings (old people's shelter, dormitory, etc.);
  - c. Homeless people;
  - d. Migrants;
14. TB staff
15. Miners
16. Children (including ROMA children)

#### 4. Key Population Prioritization

##### *Process*

Prioritization workshop participants were briefed on the goals and objectives of the workshop before the start of the work, as well as the meaning and description of the work assignment, the prioritization table and grading system and the list of key populations to be prioritized. Participants were divided into three small groups prior to the assignment, each with small group was assigned to discuss five key populations. They were tasked with following the prioritization system and evaluating each key population separately and subsequently presenting their work in plenary. After discussing and comparing the results in plenary and three most relevant TB key population were selected:

##### *Stakeholders involvement*

Involvement of both governmental nongovernmental and community organizations was very important because it enabled different points of view to be taken into consideration and resulted in a productive discussion about the main barriers and needs of people affected by TB. The participant NGOs have experienced working with persons affected by TB and have the expertise to speak as their representatives. The participant list includes organizations working

with PWUDs, as they were one of the risk groups. Those representatives outlined that PWUDs have additional special needs when it comes to TB treatment and awareness. It was also indicated by the representatives that the risk groups of PWUDs and former prisoners affected by TB in many cases may be the same persons, considering the drug policy in Georgia.

The three prioritized key populations, with their scores and the rationale :

Key population	score	rationale
People who Inject Drugs	5	Drug consumption in Georgia is considered a law violation. Because of this PWUDs are a closed group where it is harder to implement services provided by the government. Regardless this is the group which needs awareness rising and rights protected.
Internally displaced People	4	TB has re-emerged as a serious public health problem in Georgia, after declaring the independence from Soviet Union. Big waves of internally displaced persons had to move to different region and live with minimum comfort environment, which rised TB diagnois.
Former prisoners	5	There is a high rate of TB transmission in the prisons, as many persons are located in one area, with minimum comfort. Prisoners have the experience of treatment in jail as the program is implemented within the prison. They may have different valued expe-rience.

## 5. Data Collection

### *Methods used to find information*

Qualitative information to identify stigma, gender, legal and any key population-specific barriers was collected by the following methods:

- Desk research
- Interviews with key informants (experts)
- In-depth interviews - with TB patients, their family members, service providers;
- Focus groups

The assessment protocol, including interview guides, was submitted to the NCDC Bioethics Board on December 3, 2019 and approved on December 9, 2019.

The table below provides an overview of the data collection process, covering the identified respondents, method, number of participants, how the participants were chosen.

## Data collection table

		Method	Number of participants	Instruments in CRG Integrated Protocol	Participants
1	People with or had TB (PWTB) – General	IDI	30 (gender balance): 7 PWUD, 7 people with the history of imprisonment, 7 IDP, 2 LGBTQI, 7 general population	Illness and Treatment Narrative in-depth interview guide	PWTB (gender balance) diagnosed in the past 5 years
2	PWTB - General	FGD	10	PWTB-Stigma focus group discussion guide - General	PWTB (gender balance) diagnosed in the past 5 years
3	PWTB – Women	FGD	6	TB-affected Individual Focus Group Discussion Guide – Gender	Female PWTB diagnosed in the past 5 years
4	PWTB – Men	FGD	10	TB-affected Individual Focus Group Discussion Guide – Gender	Male PWTB diagnosed in the past 5 years
5	PWTB – KP PWID	FGD	10	TB-affected Individual Focus Group Discussion Guide – Selected Key Population	KP PWTB diagnosed in the past 5 years
6	PWTB – KP people with the history of imprisonment	FGD	6		For KPs that are gender sensitive (e.g. PWUD, female sex workers), the 10 participants will be split into 2 groups by gender (5 females, 5 males)
7	PWTB – KP IDP	FGD	6		
8	PTWB Family	FGD	6	Family-Stigma focus group discussion guide + gender aspects	Family members who provided care to their PWTB family members who were diagnosed in the past 5 years
9	Community	FGD	10	Community-Stigma focus group discussion guide	Local residents of 2-3 districts from which TB cases were reported in the past 5 years
10	Healthcare Workers (HCW)	FGD	10	HCW-gender focus group discussion guide (all 10 participants)	HCWs who provided services to PWTB in the past 5 years
11		FGD	10	Healthcare Provide Focus Group Discussion Guide – Selected Key Populations and Human Rights (all 10 participants)	
12	Stakeholders – Key Informants	KII	25	Key informant interview guide	National policy makers and experts (legal/human rights, gender, stigma and the three selected key populations); NCDC and the NTP.
13	Core Group	FGD	6	Law and Policy Environment	National and local policy makers (health, social, law), national experts (legal, gender, KP, stigma) and media workers
Total participants: 145					

### Inclusion criteria for participants

All participants (mentioned above) met the following criteria were 18 years or older. All the participants provided informed consent to use the data in the evaluation process. The respondents were: 1. the representative patients from the 2018/2019 cohort or individuals who have been diagnosed for the past 5 years. 2. Health care workers as providers of treatment and patients with major TB were available at treatment facilities selected by the governing government institutions. 3. Target informants selected through local government agencies and civil society organizations. The structure was applied to choosing the respondents for each topic, accordingly to the table:

Legal environment	Participants	Gender
<ul style="list-style-type: none"> <li>• A person affected by TB who has been diagnosed for the past 5 years And / or</li> <li>• Interested in or working in the field of human rights is of legal relevance to TB Response processes.</li> </ul>	<ul style="list-style-type: none"> <li>• Cohort member in 2018 or 2019</li> <li>• Cohort family member in 2018 or 2019</li> <li>• Member of the last cohort community (so-called leaders)</li> <li>• Cohort healthcare providers in 2018 or 2019</li> </ul>	<ul style="list-style-type: none"> <li>• A person affected by TB who has been diagnosed for the past 5 years And / or</li> <li>• Interested in or working in gender related to TB Response processes Target population</li> <li>• A person affected by TB who has been diagnosed for the past 5 years And / or</li> <li>• Consider themselves one of the above target population groups. And / or</li> <li>• Interested in or working with one of the above target populations and is associated with TB Response (TB Response)</li> </ul>

# Assessment Results

## 1. Legal/Human Rights

Literature review of country-specific information (country's laws, reports)

We have to divide human rights legislation in Georgia into two parts. Both domestic and inter-national law have human rights, which in turn relate to the rights of patients, and are specifically needed for patients. Human rights are protected by Georgian law including the Constitution<sup>1</sup>, the Law on Health Care<sup>2</sup>, the Law on Patients' Rights<sup>3</sup>, the Law on Tuberculosis Control<sup>4</sup>, the Code of Imprisonment<sup>5</sup> and the Law on Imprisonment<sup>6</sup>, which covers the rights of prisoners and regulates the penitentiary system, while protecting the labor rights of individuals Constitution as well as more specific laws, such as Labor code<sup>7</sup> and Law of public service<sup>8</sup>, according to the desk review, patients' rights may be violated in this regard. As conducted assessment showed there is a need to discuss the Law on Medical Practice<sup>9</sup> in Georgia which excludes the legal responsibility of physicians, whether violate confidentiality or misuse of right. There is also a Law on Social Assistance<sup>10</sup> in Georgia, which enforces the human rights of the state to receive an allowance for certain social vulnerabilities. National Strategy for Tuberculosis Control in Georgia 2019-2022<sup>11</sup> has also been developed. It ensures the proper functioning of the Tuberculosis Prevention and Control Legislation, which regulates the right of a citizen to receive quality medical care in a non-discriminatory environment, while protecting universally recognized human rights, freedoms and guarantees.

Highlight legal/human rights-related service access and provision barriers (TB Journey)

- 1 Constitution of Georgia - <https://matsne.gov.ge/ka/document/view/30346?publication=35>
- 2 the Law on Health Care - <https://matsne.gov.ge/ka/document/view/29980?publication=42>
- 3 the Law on Patients' Rights - <https://matsne.gov.ge/ka/document/view/16978?publication=11>
- 4 Law on Tuberculosis Control - <https://matsne.gov.ge/ka/document/view/3104252?publication=2>
- 5 the Code of Imprisonment - <https://matsne.gov.ge/ka/document/view/91612>
- 6 the Law on Imprisonment - <https://matsne.gov.ge/ka/document/view/11968?publication=34>
- 7 Labor code - <https://matsne.gov.ge/ka/document/view/1155567?publication=13>
- 8 Law of public service - <https://matsne.gov.ge/ka/document/view/3031098?publication=29>
- 9 Law on Medical Practice - <https://matsne.gov.ge/ka/document/view/15334?publication=21>
- 10 Law on Social Assistance - <https://matsne.gov.ge/ka/document/view/23098?publication=13>
- 11 National Strategy for Tuberculosis Control in Georgia 2019-2022. <http://www.georgia-ccm.ge/wp-content/uploads/National-Strategy-for-Tuberculosis-Control-in-Georgia-2019-2022.pdf>



	Provision barriers in Legal/Human rights	Review of local legislation
I Key Barriers to Recognizing Symptoms	Lack of awareness in the society about the symptoms of TB disease.	The Law on Tuberculosis control obliges state authorities to develop mechanisms for TB control, in particular Article 9, Chapter 1, deals with TB prevention activities and activities, and Subparagraph (D) explicitly obliges implementing authorities to provide information on TB. Conduct Social-Educational activities.
II–III Key Barriers to Seeking Care and Key Barriers to Getting an Accurate Diagnosis	Lack of awareness among family physicians, which leads to a late react and delay patient's referral.	Awareness of physicians should also be governed by a state structure, as mentioned above, as well as a «law on medical practice» obliging a physician to pursue his career and receive continuous education. Also, according to the Law on Healthcare Article 48 obliges the state to take care of doctor's awareness.
	Mis-use of right by family physicians, which involves conducting expensive examination in the clinic.	According to Article 30 of the Law on Health Care, medical personnel are required to be guided by ethical values; they are obliged to act only in the best interests of the patient. They are also obliged not to act in favor of themselves or any third party in the process of dealing with the patient. The requirement to conduct expensive examinations violates the requirements of this article.
	Geographical barriers have been identified in the regions, as there is a discriminatory approach to people coming to the capital to conduct surveys, where services are provided in their place of residence, which cannot be provided in the capital and cannot receive services free of charge and pay.	Discriminatory treatment violates the rights of a person guaranteed by both international law and national law. Pursuant to Article 6 of the Law on Health Care, it is inadmissible to discriminate patients on any ground. Both before and after treatment.
	Human rights to work are violated when the job is not maintained and lost due to prolonged treatment.	TB treatment includes hospitalization for a prolonged period of time, and further treatment that prevents a person from being employed and productive at the workplace.  Georgian legislation generally protects labor rights as set forth in the Constitution, and the Labor Code does not provide for the maintenance of workplaces in the treatment of patients.  An employer may terminate an employment contract if the term of employment exceeds 40 calendar days in a row, or within 6 months the total term exceeds 60 calendar days.

<i>II–III Key Barriers to Seeking Care and Key Barriers to Getting an Accurate Diagnosis</i>	<p>Some patients in prison refuse to take medication to make their condition worse and to be released on parole.</p>	<p>The domestic law of the country regulates the rights of prisoners by the Law on Imprisonment and the Code of Imprisonment. Article 67 of the law provides that a prisoner shall be released from prison on account of illness. A prisoner must have an incurable illness or very serious health condition. The court shall discuss the matter and decide based on a health condition. The Code of Imprisonment also provides for the release of a convicted person on the grounds of Article 39. The severity and form of the offense shall be taken into account during the exemption provided for by law. This entry in the law creates a view for prisoners that they will inevitably be released from prison if they are in poor health. Because of this, they refuse treatment and willfully burden themselves.</p>
	<p>At school: «The teacher himself demanded that no student attend from night.» «She was not allowed to go to school» «Attempted suicide»</p>	<p>These four cases can be dealt with in one context, violating the right to equality/prohibition of discrimination. Three out of four cases are in a public institution and the third in a private clinic. Nonetheless, the state is responsible for the activities performed by the health care provider and physician, whether independent or in a public institution, to ensure that the physician is impartial and free from discrimination. As for violations in public institutions, kindergartens, and schools, it is inadmissible to discriminate because of a person's health of former health condition.</p>
	<p>«Uncle had tuberculosis and the kid was kicked out of the kindergarden.»</p>	
	<p>The patient had a baby in the kindergarden, and when they heard about her TB diagnosis, they kicked the baby out from the kindergarden.</p>	
	<p>The patient was fired from work because of his medical condition.</p>	
	<p>The person was denied service of a dentist and was told to go to a «special» dental clinic.</p>	
<i>IV Key Barriers to Beginning Treatment</i>	<p>When a person is socially vulnerable and receives an incentive to pay for treatment, the state allocates that amount to an income source and grants it a score that, as a result, opens or declines social assistance, creating another barrier.</p>	<p>The country's domestic law provides for socially vulnerable people (with financial or housing problems and income problems) to provide financial support. The state evaluates them by scores and distributes a living wage. The above relationship is governed by the Law on Social Assistance. This Law applies to persons legally residing in Georgia, who require special care, needy families and homeless persons. According to Article 7, family allowances are granted to families for the sake of improving their social and economic status. Contributing to the Law on Tuberculosis Control, the social welfare watchdog considers the income and deducts the living allowance because they believe their socioeconomic status has improved.</p>



IV Key Barriers to Beginning Treatment	The person was delayed for 2 months to receive 100 GEL of incentive funds for treatment.	The Law on Tuberculosis Control provides for the transfer of cash incentives to a patient under Article 17. The State is required to provide it promptly as long as it is encouraging and adherence. It also provides for transportation costs and additional expenses when the patient is late and has to cover it at his own expense or if he or she does not have treatment.
V Key Barriers to Getting Treatment Adherence Support	«The patient had difficulty staying in one of the tub dispensaries, there were infrastructure problems and there was no water.»	Article 6 of the Health Care Law imposes an obligation on the State to control the management of health care, while its Section (k) obliges the State to maintain sanitary and hygienic standards in the field of health care and to have epidemiological control. When the TB facility lacks water and has infrastructure problems, the control mechanism is violated by the state.
	The cured patient wanted to study at the police academy and was not accepted because of his medical record.	Article 27 of the Constitution of Georgia protects the right to education. Everyone has the right to receive education and to choose his form. This implies that the restriction of this right due to health conditions is a violation of the right to human education.
General	When a person can infect other people with TB involuntary isolation act does not work. There is no mechanism to use. This does not mean that person will be forced to have a treatment is just means that person will be involuntarily isolated.	The law on Tuberculosis control is an involuntary isolation mechanism. Article 15 sets out the terms and conditions for its use. Since there is no patient protection under Article 16, such as housing, food, clothing, etc. This mechanism does not work and we have not had cases of involuntary isolation for the last 5 years, according to the records of the Tbilisi City Administrative Court.
	The public service is asking for information about TB disease whether the person is being treated for TB or not.	There is a Law on Public Service in Georgia that lists the mandatory documentation required by a public agency when seeking employment. Article 17 of this law specifies which a person cannot be employed in public service. There is an «E» section in this list that states that a person cannot hold a public office unless his or her medical report satisfies the requirements for the post. The list of documentation does not include the requirement to report tuberculosis. This is done by a public agency arbitrarily. The person had completed treatment at that barrier, which meant that he was perfectly healthy and that his former patient history should not have prevented him from performing public service.

During the work on desk review several gaps were identified. There is a lack of information about safe workplace and involuntarily isolated people with TB last 5 years. There are no specific cases about discrimination facts which are provided in medical facilities. Information about personal data rights violations in medical facilities and service provides organizations are not available. The attitude towards the LGBT community and the availability of health services for them and their problems were not identified, there is no such documented evidence to know.

Assessment will contribute to understanding of the legal environment and in TB in Georgia. In the end there will be a better understanding of barriers which causes termination of treatment or not starting treatment at all, or ending the treatment. Will be discussed specific cases about human rights violation and will be determined the problematic behavior in service provider and medical facilities. In conclusion there will be determined the problematic areas and fixing ways.

It should be noted that in the course of the interview, during face-to-face interviews and focus groups, when talking about legal aspects, respondents did not specify important details: what exactly happened, where it happened, by whom it was committed to the fact that with respect to the fact, what were the results of discrimination / violation of the right and etc.

## Gender

Article 11 of the Constitution of Georgia<sup>12</sup> and the Law on Gender Equality<sup>13</sup>, guarantees equal rights and opportunities for women and men, and recognizes the need for special measures for women and men to achieve justice and eliminate inequality.<sup>14</sup>

Gender configures both the material and symbolic positions that men and women occupy in the social hierarchy, and shapes the experiences that condition their lives. Gender is a powerful social determinant of health that interacts with other variables such as age, family structure, income, education and social support, and with a variety of behavioral factors.<sup>15</sup>

The National TB Strategy of Georgia for 2019-2022,<sup>16</sup> however, implies equal access to TB services regardless of gender or other social status, but does not separate the need for gender-based interventions. The strategy emphasizes that special attention should be paid to certain target groups, including vulnerable populations. These groups are: inmates, ex-prisoners, people with HIV, drug users. The gender difference in the strategy is mentioned only when describing the epi-demic situation, which highlights that a large proportion (70%) of new and recurrent (relapse) TB cases come on men: the TB male/female ratio is 2:1.

Georgian National Strategic Plan for Tuberculosis Control in Georgia 2016-2020 (NSP)<sup>17</sup> stipulates support to two types of research activities: i) clinical research, including participation in the international medical research / clinical trials; and ii) operational research in priority aspects related to implementation of TB control interventions in Georgia. Thus, gender responsive approach to TB is not supported by the research neither by national programs.

A study performed by Curatio Foundation in 2017<sup>18</sup> highlights the factors that influence to the treatment adherence, such as family and community support, financial burden, knowledge that are greatly derived and dependent on persons gender. Adherence support is a key component of the TB program. It is especially relevant for patients with M/XDR-TB, who need to undergo lengthy (up to two-year) treatment, have daily visits to health facilities and often suffer from

12 Amendments adopted by the Parliament of Georgia in 2017  
<https://matsne.gov.ge/en/document/view/30346?publication=35>

13 Adopted by the Parliament of Georgia in 2010  
<https://matsne.gov.ge/en/document/download/91624/3/en/pdf>

14 Geostat.ge, Women and me in Georgia, 2018 [https://www.geostat.ge/media/23369/WM\\_ge-2018.pdf](https://www.geostat.ge/media/23369/WM_ge-2018.pdf)

15 WHO, 2004

16 National Strategy for Tuberculosis Control in Georgia 2019-2022  
<http://www.georgia-ccm.ge/wp-content/uploads/National-Strategy-for-Tuberculosis-Control-in-Georgia-2019-2022.pdf>

17 National Strategic Plan for Tuberculosis Control in Georgia 2016-2020  
<http://tsp.ecom.ngo/files/Tuberculosis-National-Strategic-Plan-2016-2020.pdf>

18 Barriers and Facilitators to Adherence to Treatment Among Drug Resistant TB Patients in Georgia, 2017, Curatio foundation  
<http://curatiofoundation.org/factors-that-enhance-or-hinder-treatment-adherence-among-drug-resistant-tb-patients-in-georgia/>

serious adverse effects caused by TB medicines. In addition, various social and economic factors often prevent patients from completing treatment, such as the need to resume work for maintaining family income. The main factors that enhance or hinder adherence to treatment are as follows: the organizational structure of TB treatment and surveillance services; regulations; the financial burden; the knowledge, attitudes and practices towards TB treatment; personal qualities (behavioral traits); side-effects caused by the treatment; individual interpretation of “illness” and “wellness”; family, and community support.

Georgian women have slightly better treatment outcomes compared to men. While there are no national studies to explore this phenomenon, Curatio Foundation states, and those patients who had successfully completed TB treatment stated that one of their main sources of motivation to complete treatment was the need to take care of family members, in addition to their own health. These patients had a correct understanding of the seriousness of the disease and related risks, so they tried to complete the treatment in order to avoid creating problems for their family members and friends. This could be one of the explanations of women’s better performance, since they may feel more responsibility towards their family and children; “... My motivating factors were my child and husband. I did not want to do any harm...” A patient who has successfully completed treatment. (Curatio, 2017)

According to the information provided by The National TB Center during the last three years, new and relapse cases of TB-HIV co-infection success rates in women, is lower than in males. However, no evidence exists to explain these differences.

According to National strategic plan for TB (2016-2020), among new TB cases registered, almost 70% are males. The disease affects mainly young and the most economically productive part of the population: almost two-thirds of all new TB cases are aged between 15 years and 44 years. Although HIV infection is mainly found among males, the proportion of women affected by HIV is on rise and reached 31% in 2014. HIV largely remains concentrated among key affected populations: men having sex with men (MSM), people who inject drugs (PWID), and sex workers (SWs). Contacts’ investigation, screening and active case finding for TB among LGBT community including people living with HIV estimates that the burden of undetected tuberculosis is substantial in Georgia, especially in high-risk groups. Significant delays in diagnosing TB and initiating the appropriate treatment are likely in people with limitations in access to health services (NSP 2016 -2020).

Studies on the knowledge of TB among transgender individuals are practically nonexistent in Georgia. National report on the violation of human rights of gay men, other MSM and trans people, in particular right to health, in Georgia in 2018<sup>19</sup> describes the case of violation of health and human rights. Transgender woman who happened to have pneumonia was transferred to the Tuberculosis center. The case describes disdainful attitude towards the patient from the doctors on duty. They were using phrases like “Is it a girl or a boy?”, “Are they wearing nail polish?”, “Seems like you were at a gay club and that’s why you’re sick.” Therefore, to understand the barriers transgender people face in accessing TB prevention, testing and care services collecting relevant data and its analyses should be supported. Apart from this relevant training on gender and human rights should be conducted for health service staff.

A commendable research by Curatio Foundation in 2017 shows the existence, frequency and management of side effects considerably influence adherence to TB treatment. Many patients participating in the research talked about treatment related physical and mental side effects. All lost to follow-up patients named side effects as one of the main reasons for interrupting the treatment. Effective management of side effects requires medical personnel to be alert and have special knowledge and experience (Curatio, 2017).

The National Center for Tuberculosis has also analyzed gender-based treatment rates over the past three years. The analysis shows that in the new and relapse cases, as well as in the treated cases from 2013 to 2017, the success rates of treatment in women are slightly better than in men. The only data for 2017 among treated patients are exceptions, where the rate of successful treatment among men is slightly higher than that for women (64% vs 61%, respectively). However, these differences are not statistically significant for gender (“Research on knowledge, attitudes and practices on tuberculosis in Georgia in high-risk groups and the general population” Healthcare Research Union, 2019. The research has been done under the Global Fund grant and was shared with “New Vector” by the Health Research Union representative).

According to World Health Organization, men are significantly more at risk of contracting and dying from TB than women. Research findings uniformly suggest that prior to adolescence there is little difference between men and women in terms of their TB infection rates. From approximately age 15 onwards, however, when both biological and social changes associated with adolescence differentiate the sexes more markedly, men begin to overtake women in their rates of infection. Moreover, as they grow older, men have a higher likelihood of progressing from infection to disease. The same tendencies are observed in Georgia (Healthcare Research Union 2019).

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19 National report on the violation of human rights of gay men, other MSM and trans people, in particular right to health, in Georgia in 2018  
<http://www.equality.ge/wp-content/uploads/2019/10/403330988-National-Report-on-the-Violation-of-Human-Rights-of-Gay-Men-Other-MSM-and-Trans-People-in-Particular-Right-to-Health-in-Georgia-in-2018-1.pdf>

Other behavioral differences between men and women that may contribute to higher risk for infection among men and progression from infection to active TB from a weakened immune system include smoking, alcoholism, migration and in some cases, imprisonment, etc. (Healthcare Research Union 2019).

According to the Center for Tuberculosis, HIV testing in recent years has increased significantly from 67% in 2014 to 93% -94% in 2016-2018. The coverage of TB patients with HIV testing is identical between men and women. But, diagnosing of non-pulmonary tuberculosis is difficult in women and requires additional efforts. Women with pulmonary TB have different symptoms from men and may not test positive on microscopic examination of the sputum, or that TB lung lesions might not be as severe in women as in men, resulting in women not being accurately diagnosed. TB progresses more quickly in women of reproductive age than in men of the same age group. Women have a higher prevalence of extra-pulmonary TB (TB infections that occur outside the lung) than men. This is particularly so for genital TB, which is difficult to diagnose, and has been identified as an important cause of infertility in settings with high TB incidence (this finding is highly predominant in our Key Informant Interviews and agrees with UNDP 2015 report).

The tools used in the gender study in HRC research is to determine if other vulnerable groups, such as people with disabilities and older people, including older women, are identified in TB and HIV/AIDS programs. Stakeholders note that the aforementioned groups are not acknowledged in the strategic documents, since their specific needs for access to HIV and TB services are not supported by any data or practical observations (Healthcare Research Union 2019).

There are several surveys among health care workers on HIV/TB knowledge, stigma and discrimination awareness and attitudes of medical staff. However, there was no study of gender awareness of medical personnel in Georgia (Healthcare Research Union 2019).

Specific policies for women and girls are generally not developed in the country regarding TB. Specific policies for men and boys are generally not developed in the country regarding TB. LGBT-oriented policies or special services are not available in the country. There is no data on the number of transgender people in the country. Their vulnerability to TB or the prevalence and specific needs of this disease have not been studied (Healthcare Research Union 2019).

Moreover, non existence of gender-sensitive statistics for national HIV/TB programs neither National gender-sensitive indicators and national reporting standards to determine what type of data should be routinely presented (at least annually) for HIV and TB programs.

As already mentioned in 2017 Curatio Foundation performed the study highlighted the factors that influence to the treatment adherence. However, unfortunately data is not gender segregated and neither qualitative analysis have been done due to better understanding gender dimensions to treatment adherence.

Moreover, gender disparities of side effect management needs to be further investigated and put in treatment guidelines.



Data Provided by The National TB center shows TB death is much higher in men than in women. This can be connected to treatment adherence issues and other social factors; however, the research on this is complex and needs further development.

Besides, there is an idea that men had a higher level of TB-related health literacy than women, and this disparity corresponded with a gender-related difference in general literacy. In addition, both general literacy and health literacy are important predictors of health status; Unfortunately, articles and studies supporting those interpretations about Georgia alone do not exist.

It should be underlined with a red bold line the fact that cases identified in our assessment and barriers revealed on TB Journey Stages are not always covered with equal and relevant research information and there is a lack of appropriate supporting scientific data.

### **New Findings**

From **Focus Group discussions** and various **Interviews** became crystal clear the condition which is also tightly linked to the key barriers, that beginning treatment and fear associated with TB seems to have a greater impact on women than on men, and often leads to placing women in an economically or socially precarious position. Because the health and welfare of children is closely linked to that of their mothers, TB in women can have serious repercussions for families and households.

Because of gender differences in the division of labor and in roles and responsibilities, tuberculosis affects women and men differently. In one assessment, women patients reported inability to spend time on childcare, and difficulty in carrying out household chores because of the deterioration in their physical condition. While male patients reported distress because of loss of income and inability to contribute adequately to household expenditure: "Men reported feeling of being unnecessary, developing suicidal thoughts which sometimes leads to stopping the treatment".

Focus group discussions reveals that gender-related disparities in TB care may stem from gender-based differences in the barriers and delays that limit access to TB services. Gender differences in barriers that limit access to TB services exist at the individual and provider/system levels. These barriers include the direct and indirect costs of seeking TB services; power over family budget; temporary or permanent employment; distance to TB services and access to transportation; lack of TB-related knowledge and education; distinct gender-specific roles and status in the family; health provider suspecting TB (in women TB is suspected less often than in men – this leads to misdiagnosis from physicians); number and types of providers seen; adherence with national TB program guidelines and female and LGBT patient satisfaction with TB services.

Regarding health literacy, assessment revealed a clear gender disparity in TB-related knowledge.

According to WHO, UNDP and justified by our focus group discussions considering women's

position in the society women's health may not be considered as important as that of male family members, or because TB in women is more stigmatized than in men – “Women with TB may face a divorce from their husbands on the grounds of having TB and stop having access to their children; (with the force from the partner, the family members)” – focus group.

Gender inequality, especially when it comes to healthcare and human right slows down the development of society, free spirit, modern thinking, and public attitude and badly hits country economy. Based on these considerations and worldview it is extremely important as fast as possible, in a very brief loop of time recognize all the barriers that have been discovered and work hard to address and solve them. By its importance and significance this current assessment will certainly help to overcome gender-related TB barriers and contribute refine difficulties caused by data lacking.

## Key Populations

### Former Prisoners

there are three state programs in the penitentiary system: state programs for the management of TB, HIV/AIDS and hepatitis C. These programs are implemented in full compliance with the national treatment guidelines for the respective diseases. Report of the European Committee for the Prevention of Torture (CPT) <sup>20</sup> visit positively assesses progress in the diagnosis and treatment of TB, C-hepatitis and HIV.

TB tests are mandatory. The first TB examination by chest X-ray is carried out to the prisoner while in detention, (upon admission to prison, after the trial) and the repeated examinations are conducted every 3 months. In case of doubt, additional diagnostic tests are performed. New generation medicines, including Bedaquiline and Linezolid are used to treat the complicated forms of tuberculosis; since September 2015, the penitentiary system has begun treatment of all the “failed treatment” in the penitentiary system with a new generation of medicines - Beddiline and Linezolid. (State TB Management Program website)<sup>21</sup>

<sup>20</sup> Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) 2018 <https://rm.coe.int/1680945eca>

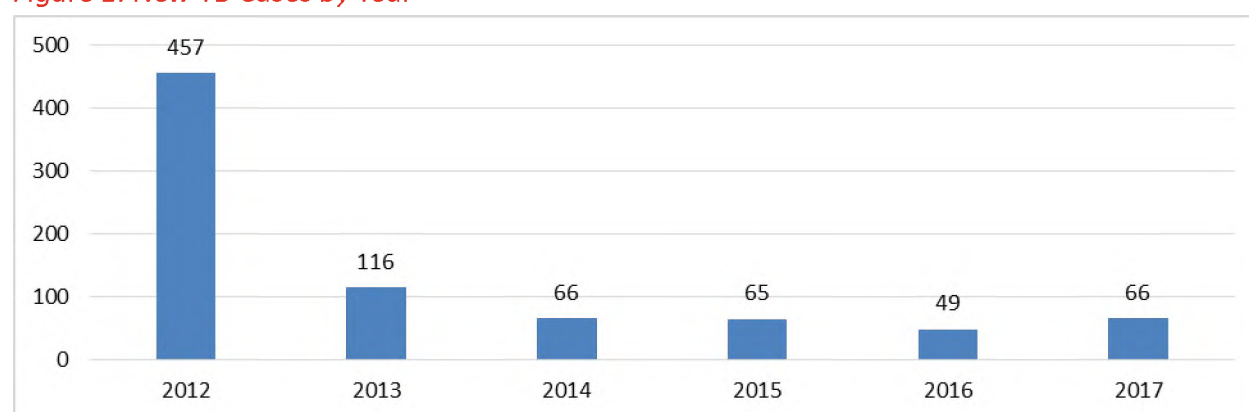
<sup>21</sup> <http://www.sps.gov.ge/ka/saqmianoba/penitenciuri-jandacvis-servisi/tuberkulozis-marthvis-sakhelmtsifo-programa.html>



Prisoners with TB are provided with a special diet, the electronic patient registration system and treatment process are fully coordinated with the National Tuberculosis Center. In 2012, the number of new TB cases was 457, according to data from the Ministry of Corrections and Legal Assistance annual statistics show in 2014 - 66, in 2015 - 65, in 2016 - 49 and in 2017 66 new cases of TB (See Figure 1). It is noteworthy that the rate of decrease in the number of TB patients in the penitentiary system is significantly higher than in the country (according to the National Statistics Office of Georgia, in 2016 there are 3329 registered cases of TB in Georgia, including 2615 new cases) and that since 2013 no cases of TB deaths have been reported in the penitentiary system.

In 2017, 2.8% (2016 - 2.1%) of new and relapse TB cases were reported in the penitentiary system.

*Figure 1. New TB Cases by Year*



When there is the background of generally positive dynamics, special attention should be paid to screening for and monitoring of DR-TB. As of 2016, there were 4 new cases of TB resistant cases, with 15 registered in 2017.

According to TB KAP 2019 (Health Research Union, 2019) the recognition of TB symptoms among the prisoners have increased. Regardless during the in-depth interviews it has been noted that doctor visits may be appointed only after days of stating the symptoms and request for an appointment.

Additionally, needs to be noted that according to the Georgian drug policy law drug use is a criminal offence and persons who use drugs may be imprisoned. This way the risks may be higher as both the prisoners and the drug users are the high-risk groups. With the weakened immune system and the prison infrastructure, those persons become more vulnerable than ever.

### **People Who Inject Drugs**

Based on information which is given by Guidance for community based organizations on tuberculosis services for people who inject drugs, TUBIDU, People who inject drugs (PWID) are often among the most vulnerable and socially excluded people in any society and are

therefore exposed to many risk factors which put them at high risk of contracting tuberculosis (TB). (Guidance for community based organizations on tuberculosis services for people who inject drugs, TUBIDU, 2014) <sup>22</sup> When compared with the general population, people who use illicit drugs have a higher risk of developing active TB disease, once infected. The higher risk of TB observed in PWID is usually the result of associated HIV infection, PWID are also more commonly predisposed to imprisonment, living in difficult environment conditions or in dwellings with poor ventilation, homelessness, poor nutrition and associated with alcoholism. All those factors complicate TB diagnosis and treatment among PWID, as they tend to have complex needs and less access to treatment. Thus, a more coordinated response to drug users' needs is required, in order to provide universal access to prevention, treatment and care services at all entry points. The community-based organizations (CBOs) working with PWID have many opportunities to have a services that can be built on to help in the fight against TB, such as understanding the local context and the needs of their members. The World Health Organization (WHO) also recommends a more active promotion of the participation of people with TB and the community in aspects of TB control. The literature provides abundant evidence about the benefits of greater involvement of communities and CBOs in various functions traditionally held by the health system. Active participation of communities and civil society in TB response allows people with TB to be identified and diagnosed more quickly, and to receive better quality care within their communities. This is especially true in the case of the poor or other vulnerable groups who normally do not have access to TB services and are hard to reach. Treatment outcomes are also improved, and people with TB become empowered by the opportunity to make decisions about the type of care that best suits them and their community. Community based TB care is cost-effective compared with hospital-based care and other conventional ambulatory care models. The guidance is intended for CBOs dealing with PWUD and the main key interventions on TB control should be as follows: Intensified TB case finding, including active case finding, contact tracing and active referral to health care services. Infection control. Isoniazid (INH) preventive therapy. Supporting clients on TB treatment and finding clients lost to follow-up. Delivering TB treatment (e.g. implementation of DOT). Informing, educating and counselling people who use drugs, those close to them and the wider community.

Drug users in Georgia are mainly covered by Georgian Harm Reduction Network member organizations; Within the framework of the project, the GHRN provided screening of drug-injecting users for early detection of TB and educational work on TB prevention and timely diagnosis;

During the 12-month reporting period in year 2016, 17,208 beneficiaries (including 560 PWID partners) were screened at the service centers through a special questionnaire on TB. Timely referral of suspected persons to TB specialized diagnostic/treatment clinics was performed.

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<sup>22</sup> <https://www.aidsactioneurope.org/en/publication/guidance-community-based-organizations-tuberculosis-services-people-who-inject-drugs>

487 beneficiaries with suspected symptoms of TB (including 8 PWID partners) were referred, 21 beneficiaries were enrolled in TB treatment program. Georgian Harm Reduction Network Report 2016)<sup>23</sup>

### Tuberculosis testing

	2014	2015	2016
Tuberculosis screening	4075	9868	17208
Referred patients	396	418	487
Patients enrolled in the TB national program	33	31	21

In 2017, drug services were provided to 10370 drug users. Abstinence-based outpatient and inpatient treatment was provided, to 14% of patients (1473 people) and 8897 individuals were involved in the progress of opioid substitution therapy, including 33 women. 1832 people were involved in the Suboxone Substitution Program, while 7065 were involved in the Methadone Substitution Program, including 491 (487 men and 4 women) in the penitentiary system. The majority (44.1%) of those involved in the replacement program were age 35-44. Majority (73%) of those involved in abstinence treatment were provided with inpatient care.

As mentioned the data mostly focused on the patients that were involved in the substitution therapy of received services at the Harm Reduction points. Needs to be outlined that depending on the in-depth interviews, it occurs that persons injecting drugs, who are not involved in the mentioned services, are less likely to engage in the TB treatment. Reason for this is that the persons who inject drugs fear that they might be exposed to relevant authorities. According the drug policy in Georgia drug use is a criminal offence.

On the other hand, it is confirmed that the treatment facilities do not have the obligation to expose a person because of their drug use status. In the opposite, the confidentiality is a priority. Regardless this information is not spread enough to gain the trust of this group.

As mentioned drug users served by the Harm Reduction Network are being referred to the TB center after going under the TB questionnaire screening. Regardless the TB procedures are free of charge and covered by the government, persons referred by the CSOs undergo paid procedures and the reference is valid only when prescribed by the family doctor.

<sup>23</sup> [http://hrn.ge/assets/uploads/%E1%83%AC%E1%83%9A%E1%83%98%E1%83%A3%E1%83%A0%E1%83%98%20%E1%83%90%E1%83%9C%E1%83%92%E1%83%90%E1%83%A0%E1%83%98%E1%83%A8%E1%83%98/2016\\_%E1%83%90%E1%83%9C%E1%83%92%E1%83%90%E1%83%A0%E1%83%98%E1%83%A8%E1%83%98.pdf](http://hrn.ge/assets/uploads/%E1%83%AC%E1%83%9A%E1%83%98%E1%83%A3%E1%83%A0%E1%83%98%20%E1%83%90%E1%83%9C%E1%83%92%E1%83%90%E1%83%A0%E1%83%98%E1%83%A8%E1%83%98/2016_%E1%83%90%E1%83%9C%E1%83%92%E1%83%90%E1%83%A0%E1%83%98%E1%83%A8%E1%83%98.pdf)

adherence to long treatment regimens can be particularly problematic for drug users. They might come across the barriers like a longer treatment periods because of their low immune system, which leads to demotivation and pessimistic approach to the treatment results. In the end resulting in leaving the treatment, after they do not see any progress after some time.

Service receiver drug users also come across the double barrier of time/resource management. Meaning that, during the day those persons have to make visits to two separate institutions for receiving substitution drugs and for receiving TB treatment drugs. Because of this they are less predictable of how they will follow the treatment till the end. Experts recommend the possibility of receiving different kind of treatment on the same spot, preferably on the ground of a trusted CSOs.

### Internally displaced persons

TB has re-emerged as a serious public health problem in Georgia. In 1997, the incidence and prevalence of active TB were approximately 100 and 200 cases per 100 000 population, respectively (unpublished data). Following Georgian independence in 1992–1993, military conflicts erupted in Georgia and resulted in several hundred thousand ethnic Georgians being forced to flee their homes in the northwest province of Abkhazia. A sizeable proportion of these internally displaced persons settled in the capital city of Tbilisi, many of them densely repopulated into former hotels, hospitals, and other residences now converted to refugee hostels.

In 2001 a study was performed to reveal the rates of the infection in those facilities. The prevalence of active TB among the hostel residents screened who had no prior history of TB was quite high, at 537/100 000. This rate is more than twice that reported for the entire Georgian population, of approximately 200/100 000.<sup>1</sup> In addition, at least 10 previously known cases of active TB from the total hostel population of approximately 4000 were excluded from the study. The prevalence of TST positivity among internally displaced persons may be higher than among other Georgians. (The International Journal of Tuberculosis and Lung Disease, Volume 5, Number 2, 1 February 2001, pp. 164-169(6) 24

Compared to the rest of the country, IDPs need special attention. According to the Ministry of Health and Social Affairs of the Autonomous Republic of Abkhazia, as of January 1, 2018, 241 900 internally displaced persons from Abkhazia, including 61 168 children aged 0-16, are registered in Georgia.

Internally Displaced Persons (IDPs) are served on 7 locations in Tbilisi, 2 in Imereti region, 5 in the Samegrelo region (polyclinic/outpatient clinic). Directly in the system of the Ministry of Health and Social Affairs of the A/R of Abkhazia there is one hospital functioning in Tbilisi. About 400 staff are employed in the medical network for IDPs.

### Referral to IDP Medical Institutions (2016-2017)

Region	2016	2017
Tbilisi	77,131	78,242
Imereti	19,964	16,383
Samegrelo	52,226	42,579
Total	149,321	137,204

According to the average incidence rates for 2015-2017, respiratory diseases are the leading cause of respiratory illness in children generally aged 0-16.<sup>25</sup>

It has been noted that considering that the IDPs are spread thru the country, and big part is located near the regions, after recognizing the symptoms, IDPs may prefer to travel to Tbilisi for a check-up rather than visit the local point. This has been connected to the mistrust and in some cases, hardness of getting the accurate diagnosis. Addressing this issue it needs to be mentioned that at this point Georgia has been equipped with 16 GenXperts around the country, which is an effective tool in getting the accurate diagnosis. Regardless the information is new to the population and it needs to be spread. (Xpert MTB by Municipality – information provided by Health Research Union)

Xpert MTB by Municipality	
Kvareli	Tsalenjikha
Gardabani	Tbilisi
Sagarejo	Xulo
Dusheti	Marneuli
Chiatura	Tskaltubo
Zestafoni	Kutaisi
Terjola	Kobuleti
Tbilisi	Akhalkalaki

<sup>25</sup> National Report regarding the health conditions of the citizens of Georgia, MOH, 2018  
<https://www.moh.gov.ge/uploads/files/2019/Failebi/16.08.2019.pdf>

- As a summary comment about specific issues regarding the risk-groups need to be made. There is a noticeable gap in the gender-related data, existing information lacks discussion about how specific genders access the services. At this point it needs to be mentioned that there is a gender disbalance connected to choosing the risk groups, as in the key populations like former prisoners and PWIDs the share of women is lower which also was noticeable during the respondent recruitment.
- The latest KAP 2019 (Health Research Union, 2019) research has provided the awareness background for the prisoners and drug users in general. But it still does not cover specific issues and barriers among those populations, but mainly addressed their awareness and knowledge about the disease.
- As a risk-group, IDPs seem to be underestimated. Their situation is mostly described along with the general barriers.

## Stigma

Stigma is defined as an undesired difference, it generates fear of the unknown, exclusion, and a set of false beliefs born from the lack of knowledge and understanding about the disease. Related to insufficient or inadequate knowledge (stereotypes). Stigma leads to prejudice, discrimination, and social withdrawal of the stigmatized person, and entails the social exclusion of the individual.

Therefore, it produces self-stigma and low self-esteem in patients, contributing to deterioration in the quality of life of individuals suffering from TB.

The need to understand how stigma influences the life of individuals is justified by the observation that stigma leads to self-denigration and to exclusion from social relationships, adding to difficulties in family and professional relationships.

According to the KAP TB 2019, conducted by Health Research Union, stigma associated with TB has decreased, but is still relevant in both anti-TB patients and former TB patients (5.1% of TB patients and 9.7% of TB patients in the past reported being shy - Patients undergoing TB treatment 18.3% and 13.1% of former patients blame themselves for their own diagnosis).

In 2016, the Curatio Foundation conducted a qualitative study to investigate factors that enhanced or hindered TB treatment adherence among sixty DR-TB patients.<sup>26</sup> The findings were grouped into structural, social, personal and health system factors. Those factors can be reviewed according to the stigma barriers.

According to the study patients conceal information about their illness and avoid communicating with others since they are afraid that people's attitude toward them will change. Some of patients do not disclose having TB to their employers because of stigma and fear of losing their jobs.



According to the same study lack of support from family and friends negatively affects adherence to treatment. With family members' support of the treatment process and accompanying the patient during DOT visits, seems to promote adherence. In addition most patients said that their decision to continue receiving medicine was a result of the negative consequences of abandoning treatment, which they saw in other patients. Exchanging information about difficulties overcome by other patients has a positive impact on adhering to treatment.

Stigmatization negatively affects medication adherence in TB patients. In agreement, stigma is an independent risk factor for nonadherence. Many studies have addressed the mechanism whereby stigma affects medication adherence. Some suggest that stigmatization lowers the self-esteem, self-efficacy, and self-confidence of patients, which in turn lowers their adherence to treatment regimens. Stigmatized TB patients may avoid taking their medications or collecting them from dispensaries to hide their condition from their acquaintances.<sup>27</sup>

The above mentioned was variously discussed during the assessment. As it appeared, patients avoid disclosing information about their diagnosis to prevent being stigmatized from their family or the surroundings. This problem is connected to the self-stigmatization and also affects the level of support the patient receives during the different stages of TB Journey. As persons with TB prefer to keep silent, there is a big chance they will self-isolate or hide their status. This may become a threat as to themselves also to their surroundings.

In addition, person diagnosed with TB are afraid their job positions will be affected by the diagnosis. Considering this, they prefer to not engage into the treatment with the fear, that their career and social position might be influenced.

For the persons who are not able to make visits to the DOT centers, the centers offer medication delivery, which is a very needed tool. Regardless, in cases, patients would refuse the DOT nurse bringing medications to their homes because someone can see them;

The stigmatization barriers do not stop at the TB status, it is also connected to double stigmatization. Meaning that the TB status of a person may appear for the public as a indicator that this person is connected to other stigmatized groups as well. To be precise society might refer to such person as someone who is a drug user or a former prisoner (this is the case of double stigma);

<sup>26</sup> Barriers and facilitators to adherence to treatment among Drug Resistant Tuberculosis Patients in Georgia, Curation international Foundation, 2017  
<http://curatiofoundation.org/factors-that-enhance-or-hinder-treatment-adherence-among-drug-resistant-tb-patients-in-georgia/>

<sup>27</sup> Nonadherence to Antituberculosis Medications: The Impact of Stigma and Depressive Symptoms, 2017  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5928710/>

The barriers also concern the fact that the TB program is free of charge and the medication fees are covered. Society believes in myths that the medicine has not undergone medical trial, is experimental and is being tested on TB patients; Regardless assessing the general impact of stigma on the treatment adherence and TB patients, there are still some gaps to fill and make out much complex issues. Regarding the existing information, it needs to be outlined that:

- Priority research in the field of TB is focused on clinical and control measures.
- The stigma regarding TB is discussed in general and this information is scattered;
- In available studies, stigma is seen as a term in itself and is not broken down into indicators that are necessary to measure stigma; (No stigma measuring scales are used)
- Information on traditional beliefs, myths, social distance, excessive sentimentality - less united under the umbrella of stigma and analyzed independently.

Additionally stigmatization needs to be discussed from different perspectives and angles:

- Situational consideration of stigma:
  - Family
  - Society / Environment
  - Workplace
  - Medical staff
- Consideration of stigma in relation to different stages of treatment (before treatment, during treatment)
- The impact of stigma as an independent and additional factor
- The legal and gender focus of stigma



## General

According to KAP TB 2019 Knowledge of free TB diagnostics and access to treatment in Georgia has improved and is quite high among people with TB (97%) as they already have the experience of free diagnosis and treatment of their own family members. Only 60-70% of respondents in other risk groups and the general population knew that the diagnosis and treatment of TB were free. This is noteworthy, as the lack of awareness of these services may delay the timely detection and treatment of TB.

During the assessment the barrier or disorientation has frequently appeared (Lack of information about where to turn for a medical check-up). This barrier delays the timely addressing to the relevant facility and heightens the risk of disease spreading.

In addition, when there is suspicion on TB, in some cases family doctors test the patient in the facility they work and do not refer them to the TB facility straight away for the free testing. Considering this the disorientation is also connected to spending more financial resources and lowering trust towards the medical personnel.

The need of frequently delivering the right information to the patients has also appeared when the patients are stopping the treatment because the physical condition improves and symptoms disappear, before the treatment is completed; misjudging the situation leads to less adherence and may result to the condition worsening again.

This barrier stands not only during the treatment, but after the treatment is complete, as well. Barrier is connected to the lack of patients' understanding of the need for follow up after completing TB treatment; it gets harder to manage, as the TB personnel is not required to deliver information to the patients after the treatment is finished, or give them a reminder. This activity seemed to be disturbing to the patients also, considering that they do not want to be reminded of their past problems. Considering this, the information needs to be repeated and delivered to them when they are still in the program and have the connection with their DOT nurses and other staff members.

Needs to be considered that outside of the chosen risk-groups, persons with HIV/AIDS were named as an important group. Regarding the group a specific barrier was outlined. It seemed that People with HIV do not have information about TB regardless of the high risk of TB;

## Summary of Findings (by TB Journey 7 Stages) Endorsed by Stakeholders at the Validation Meeting

### Key Barriers to Recognizing Symptoms (TB Journey Stage 1)

Barriers	Key Informant Interviews	In-depth Interviews	Focus Groups
Gender	Lack of knowledge/ lack of info about symptoms among women;  Women deprioritize seeking care because of family obligations	Women deprioritize seeking care because of obligations	Lack of knowledge/ lack of info about symptoms among women;  Women deprioritize seeking care because of family obligations

### Key Barriers to Seeking Care (TB Journey Stage 2)

Barriers	Key Informant Interviews	In-depth Interviews	Focus Groups
Gender	Women lack assistance and support during check-ups (women make the visits alone, men are more likely to be supported by family)	LGBTQI persons have fears of being mistreated and encountering stigma because of their identity	Financial problems of women (especially in rural areas) and less control over family budget, lead to complications in covering out-of-pocket payments during treatments
PWID	Drug users outside the methadone program are afraid to visit the health system facility because of the suspicion that they may be exposed (facing legislation issues)		

### Key Barriers to Getting an Accurate Diagnosis (TB Journey Stage 3)

Barriers	Key Informant Interviews	In-depth Interviews	Focus Groups
Legal/Human Rights	When family doctor is suspicious about TB, they may test the patients in their facility and not refer them straight to the TB center for free testing		
Gender	In women TB is suspected less often than in men – this leads to misdiagnosis from physicians;		In women TB is suspected less often than in men – this leads to Misdiagnosis from physicians;

### Key Barriers to Beginning Treatment (TB Journey Stage 4)

Barriers	Key Informant Interviews	In-depth Interviews	Focus Groups
Legal/Human Rights	State jobs may demand information about TB history, which is not demanded by the law.		
Gender			<p>Fear that “women who had TB might not get married”;</p> <p>Women with TB may face divorce from their husbands on the grounds of having TB and stop having access to their children; (with the force from the partner, the family members);</p> <p>The patients (especially women) avoid spreading information about their diagnosis to prevent being stigmatized from their family or the surroundings.</p>
Stigma	<p>Persons diagnosed with TB are afraid their relationship with family members / job positions will be affected by the diagnosis. Considering this, they prefer to not engage in the treatment.</p> <p>Society has the myths that the medicine used is not tested yet and is being tested on those persons.</p>		

### Key Barriers to Getting Treatment Adherence Support (TB Journey Stage 5)

Barriers	Key Informant Interviews	In-depth Interviews	Focus Groups
Legal/Human Rights	When a person is socially vulnerable and receives an incentive for treatment, the state allocates that amount to a source as an income and declines social assistance.		
Gender	Delayed hospitalization because of family obligations including having to care for children;		Delayed hospitalization because of family obligations including having to care for children;
PWID	Treating drug users may take more time which affects their motivation to stay in treatment		
Stigma		Person with TB face the labels of being imprisoned or using drugs (double stigma)	

### Key Barriers to Completing Treatment (TB Journey Stage 6)

Barriers	Key Informant Interviews	In-depth Interviews	Focus Groups
Gender		Men reported the feeling of being unnecessary, having suicidal thoughts – and stopping the treatment;	
PWID	Drug users may not do the regular visits and fall out of treatment		
Stigma	Patients would refuse the DOT nurse bringing medications to their homes, with fear that someone might see		

### Key Barriers to Getting Post-Treatment Follow-up Services (TB Journey Stage 7)

Barriers	Key Informant Interviews	In-depth Interviews	Focus Groups
General	Lack of patients' understanding of the need for follow up after completing TB treatment; former patients feel disturbed;		

## ANNEXES

### List of Core Group Members and their Organizations

1	Mari Chokheli	TB People,
2	Maya Kajaia	Health Research Union,
3	Gocha Gabodze	Association Pomegranate,
4	Nikoloz Mirzashvili	TB People,
5	Malkhaz Davitashvili	Center for Tuberculosis and Lung Disease Control
6	Nino Tsereteli	Tanadgoma
7	David Kakhaberi	Equality Movement

### List of Documents (and sources) Reviewed

- European Convention for the Protection of Human Rights and Fundamental Freedoms.
- European Convention on Human Rights and Biomedicine.
- The Constitution of Georgia.
- Law of Georgia on Patient Rights.
- Code of Imprisonment.
- Law of Georgia on Personal Data Protection.
- State Audit Office report. 2017
- Public Defender's Report 2018.
- Annual Statistics Report of the Ministry of Corrections and Legal Assistance 2014-2017.
- National Statistics Office of Georgia.
- Medical services in the penitentiary system, The European Union for Georgia, 2018
- Declaration of the rights of people affected by Tuberculosis - StopTBPartnership, TB People
- Barriers and facilitators to adherence to Treatment among Drug-Resistant Tuberculosis Patients in Georgia, Curation international Foundation, 2017
- Barriers and Facilitators to Adherence to Treatment among Drug-Resistant Tuberculosis Patients in Georgia, Curatio International Foundation, 2017
- Tuberculosis System Overview in Georgia, Curatio International Foundation, 2017
- WHO country profile, 2017
- WHO, Tuberculosis finance profile, 2017

- WHO, Tuberculosis profile, 2017
- INDICATORS IN THE SUSTAINABLE DEVELOPMENT GOALS ASSOCIATED WITH TB INCIDENCE, 2016
- Tuberculosis financing report, Ministry of Internally Displaced Persons from the Occupied Territories, Labour, Health and Social Affairs of Georgia, 2018
- Tuberculosis diagnostics, Governmental protocol, 2018
- TB/HIV co-infection management governmental guide, 2007
- Guidance for community-based organizations on tuberculosis services for people who inject drugs, TUBIDU, 2014
- Georgian Harm Reduction Network Report 2016
- National Report regarding the health conditions of the citizens of Georgia, MOH, 2018
- Tuberculosis management national strategy for 2015-2020 years, MOH, 2014
- Country profile, Aidsfund, 2018
- Country Profile, National Center for Disease Control and Public Health;
- Assessment of diagnostics and treatment gender barriers for HIV/AIDS and Tuberculosis, HRU, 2019
- TB KAP 2019, HRU, 2019

## Multi-stakeholder Meetings Agenda and Participants Lists

### Orientation meeting

05.09.2019

meeting opening / welcome word	17:00
TB REP 2.0 Presenting the project (goals; objectives; process) discussing project activities; presenting research process; determine core group's involvement and responsibilities in the project;	17:30
discussion	18:00

### Meeting was attended by:

1	Mari Chokheli	TB People,
2	Maya Kajaia	Health Research Union,
3	Gocha Gabodze	Association Pomegranate,
4	Nikoloz Mirzashvili	TB People,
5	Malkhaz Davitashvili	Center for Tuberculosis and Lung Disease Control
6	Nino Tsereteli	Tanadgoma
7	Konstantine Labartskava	New Vector
8	Mariam Jibuti, Organization:	New Vector
9	Lia Beritashvili	New Vector

Attendance was also confirmed by the Equality movement and Medicines Du monde – Georgia representative (Mdm). But sadly they could not attend current meeting. Information about the meeting was shared with them and they were invited in the further correspondence.



## Key Population Prioritization meeting

- AGENDA:

Coffee/Registration	09:30-10:00
<p>Welcoming word:</p> <p>“New Vector” - Konstantine Labartkava</p> <p>Word from the representative of National Center for Disease Control and Public Health - Irma Khonelidze</p> <p>Word from the representators of National Center for Tuberculosis and Lung Diseases - Zaza Avaliani</p> <p>Infectious Diseases, AIDS and Clinical Immunology Research Center –Tengiz Tsertsvadze</p> <p>PAS Center - Liliana Caraulan</p>	10:00-10:30
<p>Presentation of desk review – Community, Rights and Gender aspects of TB in Georgia ( Research consultant – Mariam Jibuti; Legal consultant – Lia Beritashvili; Gender consultant – Salome Gorelishvili)</p>	10:30-11:00
<p>Presenting assessment tools and protocol (Research consultant – Mariam Jibuti)</p>	11:00-11:30
Lunch	11:30-12:30
<p>Identification and prioritization of TB High-risk groups to be assessed:</p> <ul style="list-style-type: none"> <li>- Filling the prioritization form depending on the data provided by the desk review</li> <li>- Identification of TB High-risk Groups depending on the prioritization form</li> <li>- Presenting the results and discussing the outcomes</li> </ul>	12:30-13:45
Summarising the meeting and closing	13:45-14:15
Coffee break	14:45-14:30

### Participant List

1	Maka Revishvili	Hepa+
2	Mariam Galdava	Kanveni Clinic
3	Fati Gabunia	Infectious Disease Control Center
4	Gocha Gabodze	Asbociation pomegranate
5	Makhaz Davitashvili	National Center of Tuberculosis
6	Nino Badridze	AIDS Center
7	Natia Khonelidze	CCM Secretariat
8	Akaki Abutidze	Center for Infectious Diseases and AIDS
9	Irma Khonelidze	NCDC
10	Maka Danelia	NCDC
11	Gvantsa Kvinikadze	Network TB people
12	Nikoloz Mirzashvili	TB people
13	Nikoloz Vasnazishvili	Member of the Parlandet Health Committee of Georgia
14	Lasha Abesadze	Nev Vector
15	Zaza Avaliani	National Center for Tuberculosis Lung Diseases
16	Ia Kamarauli	Health ministry
17	Tamar Kikvidze	MDM
18	Keti Gordeladze	Georgian red cross
19	Tamar Kiladze	Hepa+
20	Kakhaber Kepuladze	Tanadgoma
21	Giorgi Soselia	MDM
22	Mari Javakhishvili	Bemoni
23	Nikoloz Chkhartishvili	AIDS Center
24	Maia Kobaidze	Bemoni
25	Mzia Tabatadze	Alternative Georgia
26	Mariam Jibuti	Nev Vector

27	Lia Beritashvili	Nev Vector
28	Liliana Caraulan	PAS Center
29	Nonna Turusbekova	TBC Consult
30	Salome Gorelishvili	Nev Vector
31	Konstantine Labartkava	Nev Vector
32	Konstantine Rukhadze	GeNPUD

### Validation meeting

Coffee/Registration	09:30-10:00
Welcoming word	10:00-10:30
Introducing the presenters	
Presenting results – TB Community, Rights and Gender barriers in Georgia (Research consultant – Mariam Jibuti; Legal consultant – Lia Beritashvili; Gender consultant – Lasha Loria)	10:30-11:30
Group work to validate and prioritize the barriers along the TB Journey	11:30-12:30
Groups report back and plenary	12:30-13:00
Lunch	13:00-14:00
Group work to validate the key recommendations	14:00-15:00
Groups report back and plenary	15:00-15:30
Group work to develop actions	15:30-16:30
Coffee break	16:30- 16:45
Groups report back and plenary	16:45-17:15
Next steps and closure	17:15 – 17:30

### Participant List

1	Ia Kamarauli	Ministry of Health
2	David Narsia	Ministry of Health
3	Gvantsa Kvinikadze	Network TB People
4	Tinatin Kharebava	Patient Union
5	Cristina Celan -	Pas Center
6	Malkhaz Davitashvili	National Center of TB
7	Nonna Turusbekova-	TBC Consultant
8	Archil Rekhviashvili	„Tanadgoma“
9	Maka Danelia	National Center of Disease Control
10	Malkhaz Berdzenishvili	“New Vector”
11	Khatuna Kutateladze	Georgian Harm Reduction Network
12	Natia Khonelidze	Curatio
13	Nikoloz Mirzashvili	TB people
14	Lasha Abesadze	New Vector”
15	Zaza Avaliani	NCDC
16	Lasha Loria	Hired Gender Consultant
17	Lali Janashia	National Center of TB
18	Keti Gordeladze	Red Cross Georgia
19	Tamar Kiladze	Hepa+
20	Nana Kaparanadze	“New Vector”
21	Mariam Chokheli	OSGF
22	Irina Grdzeldze	CCM
23	Maia Jikia	Health Research Union
24	Ada Beselia	“Alternative Georgia”
25	Mariam Jibuti	“New Vector”
26	Lia Beritashvili	“New Vector”
27	Irma Khonelidze	National Center of Disease Control
28	Mikheil Tavadze	“New Vector”
29	Konstantine Labarkava	“New Vector”
30	Konstantine Rukhadze	GeNPUD

## Key Populations Prioritization Tool Used

Based on prioritization tool in Stop TB Partnership's CRG Assessment Integrated Protocol;

	Score 1	Score 2	Score 3	Score 4	Score 5		Score 6	Combined Score to Facilitate Prioritization Discussion	
	Exposure Risks	Biological Risks	Barriers to care access	Barriers to care completion	Likelihood of new insights		Estimated (and/or official data, if available) Contribution to the Country's TB Disease Burden	Risk, Barrier and New insights Scores Sub-Total (Sum of Scores 1-5) Max 5	Total Score (Sum of Scores 1-5) Max 10
Exposure to infectious people/concentrated bacilli	Likelihood of immunosuppression/susceptibility to developing active TB	Gender, legal, social and structural barriers	Stigma, life circumstances, access continuation difficulties	Social dynamics insufficiently understood	(Active TB cases of all forms)				
0 – Low	0 – Low	0 – Low	0 – Low	0 – Low	1 – Very Low (<1%)				
0.5 – Medium	0.5 – Medium	0.5 – Medium	0.5 – Medium	0.5 – Medium	2 – Low (1-3%)				
1 – High	1 – High	1 – High	1 – High	1 – High	3 – Medium (3-5%)				
					4 – High (5-10%)				
					5 – Very High (>10%)				

Key Populations	Processing score	Final score
HIV/AIDS community	6	5.5
Persons who inject drugs	5	5
Persons in the penitentiary system	5	5
Internally displaced persons	4	4
Migrants	4	4
Homeless persons	6	6
Oncology Patients	2.5	2.5
Alcohol abuse	3.5	7.5
Heavy smokers	6	6
Persons with psychological issues	3	3
Patients on dialysis	4	4
TB staff	1.5	1.5
Children - General	2	2
Children – Roma	6	6
Persons with diabetes	1.5	1.5
Children in shelters	4	4

## Key Informant Interviews

Number of interviews - breakdown by interviewees' organizations and geographical locations

1. Lali Janashia	TB National Center
2. Badri Tezelashvili	TB National Center
3. Gvantsa Kvinikadze	TB people
4. Nika Mirzashvili	TB people
5. Kote Rukhadze	GeNPUD
6. Lasha Abesadze	New Vector - Rustavi
7. Gocha Gabodze	Pomegranate
8. Marine Gogia	Georgian Harm Reduction Center
9. Dali Usharidze	New Way
10. Marie Chokheli	OSGF
11. Lasha Tvaliashvili	Real People Real Vision
12. Medea Khmelidze	Real People Real Vision
13. Ketu Kobiashvili	TB People
14. Ketu Mindeli	Red Cross
15. Nino Osepashvili	Patient Union
16. Manana Sologhashvili	HEPA +
17 Nino Tsereteli	Tanadgoma
18 Tiko Kharebava	Adherence case manager
19. Anna Tsitsitville	(EMSEF)
20. Tamuna Gogoladze	Patient Union
21. David Jikia	Patient Union
22 David Chikhradze	Head of Gori Municipality Social and Health Service
23. Manana Ghonghadze	Gori TB Center
24. Ketevan Bidzinashvili	Union Step to the Future



Number of participants – breakdown by gender, age and other important factors

Expert interviewees chosen from four geographical locations : 20 in Tbilisi. 2 from Gori and 1 from Rustavi and 1 from Zugdidi.

From them – 16 women and 8 men

### Activity: Key Informant Interview

#### A. Individual Role

1. Can you describe your role in the TB response and why this is important?
2. How does your work relate to gender/[selected key population], if at all?

#### B. General TB response

1. From your perspective, what is going well with the TB response?  
Prompts: Law, policy, prevention, implementation, treatment targets
3. From your perspective, what needs improving in the TB response?  
Prompts: Law, policy, prevention, implementation, treatment targets

#### C. Gender/[selected key population] and TB

1. How would you describe your country's national legal and policy approach to gender/[selected key population]?
2. How do you think gender/selected key population membership determines who gets sick from TB?
3. How do you think gender/selected key population membership impacts on people's ability to access treatment and care?
4. How do you think gender/selected key population membership impacts on people's ability to link their close contacts to TB care?
5. Do you think the national TB policies take the needs of different gender/selected key population membership into account? In what ways?

#### D. Gender Issues and Tuberculosis

1. Please tell us about the Gender issues needs related to Tuberculosis.
2. Are there any specific needs for the key population in terms of gender? (With whom they have contact: drug users / IDPs / ex-prisoners)

3. Do you think gender affects the availability of treatment?
4. How would you describe the approach to national legislation and policy in your country, given the gender gap?
5. Do you think that the national tuberculosis policy takes into account the gender needs? In what way?

#### E. Building better response

Are there any ways you can think of to improve the TB response to better respond to gendered/ selected key population needs?

**Prompts: ways to decrease vulnerability and increase access to services, ways to monitor service provision**

What would need to be in place for improvements to happen?

**Prompts: Changes needed in the law, policy, practice, funding, attitudes, monitoring and evaluation processes**

Are there any available self-support groups for TB patients' social services or psychological consultations offered to patients with TB? For instance through social contracting

**Prompts: other organizations that provide such services, ways patients are supported mentally along their TB journey, how patients are informed about them, where they could find the information.**

#### F. Closing

In-depth Interviews

1. Number of interviews - breakdown by interviewees' organizations and geographical locations
2. Number of participants – breakdown by gender, age and other important factors

Total of 30 in-depth interviews were conducted in 5 regions of Georgia. chosen cities were: Tbilisi, Rustavi, Gori, Zugdidi, Batumi

By gender: 60% men, 33.3% women, 6.7% - transgender

By grouping: 7 PWIDs, 7 IDPs, 7 Former Prisoners, 7 general TB patients, 2 Transgender persons.

## In-depth interview guides used

Activity: Illness and treatment narrative interview

### A. Overview (knowledge of TB)

1. What information do you have about tuberculosis? Did you have this information before you found out about your diagnosis?  
Prompts: Illness cause and cures
2. How do you think most people in your community understand TB?  
Prompts: Illness cause and cures, do you think if TB is curable, do they think you are still contagious
3. Tell me about the times you have TB  
Prompts: Types of infection, dates of illnesses, diagnosis and treatment, number of episodes, reasons for infection
4. Did you have to ask permission to anyone before referring to health care?  
Prompts: permission from a husband, wife or other family members
5. If you have had TB more than once, were there any differences between the times you had TB?  
Prompts: Personal responses, changes in treatment processes

### B. Details on last illness episode

1. Why/how do you think you contracted TB [the last time]?
2. What made you think you were sick?  
Prompts: Symptoms, interpretation and recognition of illness
3. What did you do when you realized you were sick? Why?  
Prompts: Healthcare accessed, time after symptom appearance
4. Can you describe what taking treatment is/was like?  
Prompts: Challenges and facilitators
5. Could you tell me about treatment side effects and how you coped with them?  
Prompts: mental or physical side effects, talking to health care staff about your side effects, receiving other types of help, receiving side effect medication (free)
6. What kind of support and from whom you received during the treatment that helped you along?  
Prompts: family support, peer support, social support, how did they help

7. Can you tell me about anything else you did to improve your health?  
Prompts: Additional healing practices or medicines
8. What changes happened in your life when you were diagnosed with TB?  
Prompts?
9. Was there anyone you linked to the facility? Why? Why not?  
Prompts: facility processes for accessing TB contacts, understandings of preventative therapy
10. How long did it take from the appearance of the symptoms until coming to the general practitioner? How long did it take from GP to getting the diagnosis? How long did it take from diagnosis until beginning of the treatment?  
Prompts: possible delays, why they happened?
11. What was your motivation to begin a treatment?  
Prompts: Negative motivators and positive motivators

### C. Outlining stigma and it's influences

1. Can you tell me about getting the TB diagnosis?  
Prompts: How the information was delivered, counselling processes, support provided, understandings of illness, agreement on confidentiality
2. Who did you tell when you got your diagnosis? Why?  
Prompts: household residents, friends, employers
3. Was there anyone you hid your diagnosis from? If so why?  
Prompts: Family, employers, neighbours and what the feared responses were
4. Did the relationship towards you changed after you revealed your TB status?  
Prompts: attitudes towards you from family members or other people (co-workers, neighbours)
5. How were you treated at the facility?  
Prompts: Health care provider, security, admin staff and peer responses

6. Have you experienced stigma or discrimination,

Prompts:

stigma enacted that inhibited you from recognising TB symptoms,  
seeking care,  
getting an accurate diagnosis,  
beginning treatment,  
getting treatment adherence support,  
completing treatment or getting post-treatment follow-up services

If yes, please describe your stigma experience and how it prevented you from seeking and getting TB services.

7. Have you seen/heard of other PWTB you know personally being stigmatised or discriminated?

Prompts:

stigma enacted that inhibited them from recognising TB symptoms,  
seeking care,  
getting an accurate diagnosis,  
beginning treatment,  
getting treatment adherence support,  
completing treatment or getting post-treatment follow-up services

If yes to any, please describe their stigma experience and how it prevented them from seeking and getting TB services.

#### D. Impact of gender/key population membership on TB experience

How do you think being [insert word relevant to participant e.g. woman/man/transgender person shaped the way you experienced having TB?

Prompts:

Vulnerability to infection,  
access to healthcare,  
diagnosis and treatment,  
quality of assistance received

#### E. Closing

## Focus Groups

1. Number of groups - breakdown by key populations and geographical locations
2. Number of participants – breakdown by gender, age and other important factors

Total of 10 focus groups were conducted involving:

- TB center administration
- TB center DOT service providers
- Internally displaced persons
- People Who Inject Drugs
- Core Group members
- 3 groups with general TB patients (one male group, one female group, one mixed)
- General population
- TB patient family members

Groups took place in five regions of Georgia, specifically in the cities: Tbilisi, Rustavi, Gori, Batumi, Zugdidi.

## Focus group discussion guides used

### Healthcare provider focus group - Key population and human rights

#### A. Key population membership and perceptions - Ask for each key population

1. How would you describe the challenges faced by this population in general?

Prompts: stigma, discriminatory laws, human rights abuses, employment challenges

2. What makes [specific key population] particularly vulnerable to TB?

Prompts: vulnerability to particular illnesses, access to healthcare, stigma

3. How would you describe the TB response for [specific key populations]?

Prompts: access to care, stigma, differentiated care responses

4. What are the challenges of providing services to [selected key population]?

Prompts: access, facility attendance, treatment adherence, policy and legal challenges

5. Please talk about what types of barriers can be addressed by people diagnosed with tuberculosis in the following steps:
- Recognize the symptoms
  - seeking care,
  - getting an accurate diagnosis,
  - beginning treatment,
  - getting treatment adherence support,
  - completing treatment
  - completing treatment or getting post-treatment follow-up services

### B. Building a better response

5. How could the TB response be better designed to meet the needs of [selected key populations]?
- Prompts: ways to decrease vulnerability, ways to increase care access
6. What would need to be in place for improvements to happens?
- Prompt for: changes needed in the law, policy, practice, funding, attitudes
7. What monitoring and evaluation processes would need to be put in place to assess change processes?
- Prompts: Data collection, reporting, staffing

### C. Freedom from discrimination

1. Have you ever heard of any cases that may have appeared as a discrimination of TB patients? If yes, please provide information about the case; Was the fact stated by the patient or a healthcare provider?
2. Have you experienced stigma or discrimination (stigma enacted) yourself at work, at home or in your community that inhibited you from supporting your TB patients in recognizing TB symptoms, seeking care, getting an accurate diagnosis, beginning treatment, getting treatment adherence support, completing treatment or getting post-treatment follow-up services?

If yes to any, please describe your own stigma experience and how it prevented you from supporting your TB patients in seeking and getting TB services.



3. Have you seen/heard of other health care workers that you know personally being stigmatized or discriminated (stigma enacted) that inhibited them from supporting their TB patients in recognizing TB symptoms, seeking care, getting an accurate diagnosis, beginning treatment, getting treatment adherence support, completing treatment or getting post-treatment follow-up services?

If yes to any, please describe the stigma you saw/heard and how it prevented them from supporting their TB patients in seeking and getting TB services.

#### **D. Access to information**

1. Could you please provide describe, how patient information is received and stored? Do the patients have access to their health condition files?
2. Is there any reason, why a person can be denied for access to their health information? have you ever heard of cases when the patients received an unjustified rejection when asking for their health condition?)
3. Do patients receive any general information about TB? How is the patient diagnosis delivered to them? What kind of information do they receive about TB when the diagnosis is delivered?
4. Do patients receive detailed information about their treatment process/progress/regress?

#### **E. Access to services**

1. Do you keep the track of the visits done by the patients? Do you follow up on the missed visits?  
  
Are you aware of the patients who have problems with the access to the treatment? (because of health condition/traveling fees/etc)? how are those patients managed?
2. How would you proceed in case a patient misses their visit to get the treatment (because of health condition/traveling fees/etc)
3. in what cases could a person be denied treatment for TB? Are you aware of cases when an individual was denied treatment without giving a reason?

#### **F. Privacy**

1. Please describe the process/environment when the diagnosis is delivered to the patient.
2. How would you describe the strengths of your data protection mechanisms? Who has access to this information?

3. In what cases can the information be shared with a third party? Who is involved in giving the permission for this process?

## B. Gendered dynamics of vulnerability, diagnosis and treatment

1. Do you think men or women are more likely to get sick from TB? Why?  
Prompts: Social roles and activities, work, access to healthcare, care responsibilities, living conditions, policies
2. Imagine there were twenty people screened and found to have TB in a community screening drive. The group includes ten men, and ten women:
  1. Would the men or women be more likely to come and get care? Why?
  2. Would the men or women be more likely to complete treatment? Why?
  3. Would the men or women be more likely to bring their close contacts in for care?
  4. Do you think transgender people have any additional risks of contracting TB? If so, what are these and why? Prompts: Social roles and activities, work, access to healthcare, care responsibilities, living conditions, policies, use of preventative therapy
3. Do you think transgender people have any additional risks of contracting TB? If so, what are these and why?  
Prompts: Social roles and activities, work, access to healthcare, care responsibilities, living conditions, policies, use of preventative therapy
4. Are there any additional challenges for you in providing treatment to transgender people?  
Prompts: Stigma, treatment access, attitudes, policy
5. How do women and men participate in decision making process within their treatment  
Prompts: likeness of women and men requesting information in regards to their treatment, and degree of their participation based on gender
6. Are there any available social or support groups services , or psychological consultation offered to patients with TB ? For instance through social constructing  
Prompts: other organizations that provide such services, ways patients are supported mentally along their TB journey and men's and women's participation or request to be involved in such services  
Prompts: Changes needed in policy, gender relations, healthcare provision, attitudes

## Society - Stigma Focus Group Discussion Plan

1 What information do you have about TB disease? Where did you get this information?

2 How do you perceive stigma? Please describe several indicators of recognising TB stigma.

3 Do you have / have had contact with a person who has or has had TB? (Neighbor / friend / etc)

4 What was your attitude when you learned about this person's diagnosis? How were other members of the community perceived?

5 Has your relationship with this person changed since you heard diagnose? If yes, please tell us how it changed?

6 Have you heard of any discriminatory facts against a patient diagnosed with tuberculosis? (If so, tell us) (Specify whether this information was provided to you by the patient himself / the first source)

7 Have you heard / heard about the fact of discrimination or stigmatization of this person, which prevented:

- recognising TB symptoms,
- seeking care,
- getting an accurate diagnosis,
- beginning treatment,
- getting treatment adherence support,
- completing treatment
- getting post-treatment follow-up services?

If to any, how did you prevent this person from finding and receiving services?

8 Have you heard / heard about a person being stigmatized or discriminated against by a family member that prevented him or her from doing so:

- recognising TB symptoms,
- seeking care,
- getting an accurate diagnosis,
- beginning treatment,
- getting treatment adherence support,
- completing treatment
- getting post-treatment follow-up services?
- 

If yes to any, how has stigmatization and discrimination prevented family members from seeking treatment and services?

9 What can be done to reduce the burden on people with TB? (Political reforms, legal change, raising awareness) Specify how

## 10 Closing

### Family-Stigma Focus Group Discussion Guide

- 1 How do you perceive stigma? Please describe several indicators of recognising stigma. (regarding TB)
- 2 When was your family member diagnosed with TB? How did you feel at the time when you learned about your family member's TB diagnosis?
- 3 What were the next steps you took after learning about their diagnosis?
- 4 How is your family member perceived by other members of the family, neighbours, community?
- 5 Have you experienced stigma or discrimination (stigma enacted) that inhibited you from supporting your family member in:
  - recognising TB symptoms,
  - seeking care,
  - getting an accurate diagnosis,
  - beginning treatment,
  - getting treatment adherence support,
  - completing treatment
  - getting post-treatment follow-up services?
 If yes to any, please describe your stigma experience and how it prevented you from supporting your family member with TB seeking and getting TB services.
- 6 Have you seen/heard of other families you know personally being stigmatised or discriminated (stigma enacted) that inhibited them from supporting their family members with TB in:
  - recognising TB symptoms,
  - seeking care,
  - getting an accurate diagnosis,
  - beginning treatment,
  - getting treatment adherence support,
  - completing treatment
  - getting post-treatment follow-up services?
 If yes to any, please describe their stigma you saw/heard and how it prevented them from supporting their family members with TB seeking and getting TB services.

- 7 Has your family member socio-psychological state change since the diagnosis? If yes, please describe how.
- 8 Has your relationship with the family member changed since the diagnosis? Please describe how.
- 9 What can be done to ease the social burden appearing in front of persons with TB? Can this be regulated by law or policy?
- 10 **Closing**

### *Beneficiaries*

#### **Illness and treatment narrative interview**

##### **A. Overview (knowledge of TB)**

1. What information do you have about tuberculosis? Did you have this information before you found out about your diagnosis?  
**Prompts: Illness cause and cures**
2. How do you think most people in your community understand TB?  
**Prompts: Illness cause and cures, do you think if TB is curable, do they think you are still contagious**
3. Tell me about the times you have TB  
**Prompts: Types of infection, dates of illnesses, diagnosis and treatment, number of episodes, reasons for infection**
4. Did you have to ask permission to anyone before referring to health care?  
**Prompts: permission from a husband, wife or other family members**
5. If you have had TB more than once, were there any differences between the times you had TB?  
**Prompts: Personal responses, changes in treatment processes**

##### **B. Details on last illness episode**

1. Why/how do you think you contracted TB [the last time]?
2. What made you think you were sick?  
**Prompts: Symptoms, interpretation and recognition of illness**

3. What did you do when you realized you were sick? Why?  
Prompts: Healthcare accessed, time after symptom appearance
4. Can you describe what taking treatment is/was like?  
Prompts: Challenges and facilitators
5. Could you tell me about treatment side effects and how you coped with them?  
Prompts: mental or physical side effects, talking to health care staff about your side effects, receiving other types of help, receiving side effect medication (free)
6. What kind of support and from whom you received during the treatment that helped you along?  
Prompts: family support, peer support, social support, how did they help
7. Can you tell me about anything else you did to improve your health?  
Prompts: Additional healing practices or medicines
8. What changes happened in your life when you were diagnosed with TB?  
Prompts?
9. Was there anyone you linked to the facility? Why? Why not?  
Prompts: facility processes for accessing TB contacts, understandings of preventative therapy
10. How long did it take from the appearance of the symptoms until coming to the general practitioner? How long did it take from GP to getting the diagnosis? How long did it take from diagnosis until beginning of the treatment?  
Prompts: possible delays, why they happened?
11. What was your motivation to begin a treatment?  
Prompts: Negative motivators and positive motivators

### C. Outlining stigma and it's influences

1. Can you tell me about getting the TB diagnosis?  
Prompts: How the information was delivered, counselling processes, support provided, understandings of illness, agreement on confidentiality
2. Who did you tell when you got your diagnosis? Why?  
Prompts: household residents, friends, employers

3. Was there anyone you hid your diagnosis from? If so why?  
Prompts: Family, employers, neighbours and what the feared responses were
4. Did the relationship towards you changed after you revealed your TB status?  
Prompts: attitudes towards you from family members or other people (co-workers, neighbours)
5. How were you treated at the facility?  
Prompts: Health care provider, security, admin staff and peer responses
6. Have you experienced stigma or discrimination,  
Prompts:  
stigma enacted that inhibited you from recognising TB symptoms,  
seeking care,  
getting an accurate diagnosis,  
beginning treatment,  
getting treatment adherence support,  
completing treatment or getting post-treatment follow-up services  
If yes, please describe your stigma experience and how it prevented you from seeking and getting TB services.
7. Have you seen/heard of other PWTB you know personally being stigmatised or discriminated?  
Prompts:  
stigma enacted that inhibited them from recognising TB symptoms,  
seeking care,  
getting an accurate diagnosis,  
beginning treatment,  
getting treatment adherence support,  
completing treatment or getting post-treatment follow-up services  
If yes to any, please describe their stigma experience and how it prevented them from seeking and getting TB services.



#### D. Impact of gender/key population membership on TB experience

1. How do you think being [insert word relevant to participant e.g. woman/man/transgender person] shaped the way you experienced having TB?

Prompts:

Vulnerability to infection,  
access to healthcare,  
diagnosis and treatment,  
quality of assistance received

#### E. Closing

## CONFIDENTIALITY AND CONSENT FORM USED

**Assessment staff member:** \_\_\_\_\_

I am working with New Vector doing Assessment on a project for Global Fund. This project is trying to understand why so many people who have TB do not get diagnosed or treated to cure. In particular we are looking at the ways in which gender, stigma and the legal environment affect vulnerability to TB and access to care. We are also looking at how some populations : PWID – People who inject drugs, People with a history of imprisonment, IDPs – Internally displaced persons are particularly at risk of TB and what accessing care is like for these populations. This is to help inform better policy and health care provision.

We are including lots of different people in this Assessment, from people making policy, to people advocating for better treatment, to people who have been affected by TB.

We are gathering information in lots of different ways, including:

- Doing desk reviews
- Talking to people about their experiences of seeking, receiving and providing care;
- Conducting key informant interviews
- Conducting in-depth interviews;
- Conducting focus group discussions;

We may ask you if you are willing to participate in this Assessment. This does not mean that we think that you necessarily have TB. It just means that we think you may have a valuable opinion or expertise on the subject.

It is entirely your choice whether to participate or not, and you may choose to participate in one aspect, but not another. If you *do* choose to participate in any aspect you will be asked to sign a relevant “consent form”. This form gives me permission to use the information you provide. You may change your mind later and stop participating even if you agreed earlier. If you choose *not to* participate it won’t affect you in any way.

There are not direct benefits to you for participating in the Assessment, though we do hope that it will lead to positive change in the way TB is responded to. Some participants will receive a small remuneration for transport costs. This is detailed in the additional information sheets for the different Assessment methods.

Any communication with any of the assessment staff will be will confidential. This means that anything you say will stay private. We may discuss information amongst the assessment staff, but we have all signed confidentiality forms and we will only include anything you tell us in the written documents once we have removed any way for other people to know who the information comes from. The only time we might tell someone else what you said is when it puts someone in danger.

This Assessment has been approved by NCDC. We also have approval from all the managers of the healthcare facilities we are working in.

If you have any questions or are uncomfortable with anything you can speak to me or one of my colleagues at any time, and you may also ask to review anything I have written that relates to you. Alternatively, you can raise any concerns you may with:

Research consultant – Mariam Jibuti

Mob. +995 555 166 911

E-mail: [mariamjibuti3@gmail.com](mailto:mariamjibuti3@gmail.com)

## CONSENT FORM

Assessment of CRG barriers for high-risk TB groups in Georgia

Please note each item:

1. I confirm that I have read the information part of the research and I agree to answer the questions you asked.
2. I realize that my participation in the study is voluntary and I have the right to stop participating in it at any time without giving a reason.
3. I agree to take part in the research
4. I agree to have audio recorded of the interview

Participant signature \_\_\_\_\_

Form receiver signature \_\_\_\_\_

Date: \_\_\_\_\_



