



**Breaking the Silence:
Human Rights,
Gender, Stigma
and Discrimination
Barriers to TB
Services in**

**Georgia
Kazakhstan
Kyrgyzstan
Tajikistan
Ukraine**





**Breaking the Silence:
Human Rights, Gender,
Stigma and Discrimination
Barriers to TB Services in Georgia,
Kazakhstan, Kyrgyzstan,
Tajikistan and Ukraine**

Overview Report

November 2020

Acknowledgements

The communities, rights, and gender (CRG) regional brief was developed as part of the 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), financed by The Global Fund to Fight AIDS, Tuberculosis and Malaria and implemented by the Center for Health Policies and Studies (PAS Center) as the principal recipient.

Main writers

The document was produced by TBC Consult: Nonna Turusbekova, Kristina Zhorayeva, Peter Mok, and Samanta Sokolowski.

Peer reviewers

Technical guidance and internal review was provided by the PAS Center’s TB-REP 2.0 team: Stela Bivol, Liliana Caraulan, Svetlana Nicolaescu, and Cristina Celan.

Other contributors and external reviewers

Additional valuable inputs integrated into the overview were provided by The Global Fund TB-REP 2.0 Fund Portfolio Management team and CRG team (Alexandrina Iovita and Brice Bambara); the Stop TB Partnership Country & Community Support for Impact team (Viorel Soltan, Thandi Katlholo and James Malar); and the WHO EURO Division of Country Health Programmes, Joint TB, HIV and Viral Hepatitis Programme (Askar Yedilbayev, Andrei Dadu).

The PAS Center gratefully acknowledges the contribution of all partner organizations that supported the development of the Regional CRG Overview.

Special thanks to the organizations and teams that conducted CRG assessments and developed national reports to inform the overview:

- Georgian Network of People Who Use Drugs (GeNPUD) “New Vector” (Georgia);
- ALE “Kazakhstan Union of People Living with HIV” (Kazakhstan);
- NGO “Gender and Development” (Tajikistan) and Canadian HIV/AIDS Legal Network;
- Alliance for Public Health (Ukraine);
- United Nations Development Programme (Ukraine);
- Coalition against Tuberculosis (Kyrgyzstan);
- The Global Fund;
- Stop TB Partnership;
- APMG Health.

Content

Acknowledgements	2
Abbreviations	4
Foreword	5
Executive Summary	8
Background	15
Methods	16
Summaries of results per country	19
Georgia.....	20
Kazakhstan.....	25
Kyrgyzstan.....	30
Tajikistan.....	34
Ukraine	38
Discussion of the main barriers and solutions	43
Key populations: people with a history of imprisonment and people who use drugs	43
TB in women and GBV.....	45
Stigmatization by health care workers.....	46
People-centered approach.....	48
The role of primary health care providers.....	49
Job security and the right to work.....	50
Active case finding in rural poor	51
The role of NGOs.....	51
Uptake of CRG recommendations in the national strategic plans	54
Example of Kyrgyzstan.....	54
Example of Ukraine	55
Conclusions	56
References	58

Abbreviations

CCM	Country Coordinating Mechanism
COVID-19	Coronavirus disease
CRG	Communities, Rights and Gender
CSO	Civil Society Organization
GBV	Gender-Based Violence
DOT	Directly Observed Therapy
DR	Drug-Resistant
EECA	Eastern Europe/Central Asia
ID	Identification
IDP	Internally Displaced Person
MAF	Multisectoral Accountability Framework
MDR	Multi Drug-Resistant
MDT	Multi-Disciplinary Team
NGO	Non-Governmental Organization
OST	Opioid Substitution Therapy
PLHIV	People Living with HIV
PHC	Primary Health Care
PWID	People Who Inject Drugs
PWUD	People Who Use Drugs
RR	Rifampicin Resistant
TB	Tuberculosis
TB-REP 2.0	Advancing people-centered quality TB care – from the new model of care towards improving DR-TB early detection and treatment outcomes
TRP	Technical Review Panel
VST	Video-supported Treatment
WHO	World Health Organization

Foreword

Do you know which infectious disease is the world's biggest killer? No, not COVID-19. It is still tuberculosis (TB), and our region, Eastern Europe and Central Asia (EECA), has been hard hit. But unlike COVID-19, TB is curable and preventable, and the world committed to ending TB by 2030. We live in a time when the response to TB is being reimagined, yet we risk losing the fight. For me, this is déjà vu.

I was born in a country that no longer exists, the Soviet Union, at a time when infectious diseases such as TB were at an all-time low. The moment of hardship came in the 1990s, when our whole world crumbled around us. In the aftermath of economic reforms, almost 300 million people in 15 new countries lost their incomes and savings and had to subsist for years while our social fabric disintegrated. Eastern Europe and Central Asia quickly became the region with the highest number of people with drug-resistant TB – a clear sign of social distress and health system crisis.

Two decades later, we are living in truly amazing times for TB care. There are new rapid diagnostics that can detect TB in an hour, artificial intelligence analysis of chest X-rays provides faster and more precise screening, new drugs allow people with drug-resistant TB to be treated without hospitalization, and digital adherence tools allow people with TB to stay in touch with their doctors while taking their treatment at home. In a historic moment at the United Nations High Level Meeting in 2018, countries committed that all people with and affected by TB would have access to people-centered prevention, diagnosis, treatment, and care, as well as psychosocial, nutritional, and socioeconomic support; that communities and civil society would be meaningfully involved in the TB response; that community-based TB services would be developed and legal, gender-related, and socio-cultural barriers to TB care removed; and that TB-related stigma and all forms of discrimination would be ended.

Since 2016, together with our partners and with funding from the Global Fund to Fight AIDS, Tuberculosis and Malaria, we have been working to make health services people-centered in 11 countries: Armenia, Azerbaijan, Belarus, Georgia, Kazakhstan, Kyrgyzstan, the Republic of Moldova, Tajikistan, Turkmenistan, Ukraine, and Uzbekistan. The ultimate goal is to ensure that people with TB have their medical and social needs addressed, so they can be diagnosed on time and take the full course of treatment. We have seen a shift in the approach of national TB programs and a more prominent role emerging for civil society. The EECA region now has the fastest decline in TB incidence compared with all other regions of the world; economies and health systems have also slowly improved. Yet, the proportion of people with new and previously treated TB who have drug-resistant disease is still high, and finding people with TB who are missed by the national programs remains an important challenge. Structural barriers are at the core of failures to achieve the goals of the End TB strategy.

The TB-REP 2.0 multicountry grant aims to advance towards people-centered approaches, ensure provision of quality TB and DR-TB care and prevention, keep multidrug-resistant (MDR) TB high on the public agenda, and actively involve communities and civil society in building sustainable TB care models. The two prongs are to ensure full engagement of communities and civil society in TB prevention and care and to strengthen health systems to enable integrated people-centered TB and DR-TB care delivery systems that address the needs of key populations.

The Global Fund's strategy recognizes the urgent need to eliminate health disparities among men and women; it invests to reduce health inequities, in programs that remove human rights barriers to accessing services, and to support the meaningful engagement of key and vulnerable populations. Aligned to this, TB REP 2.0 works to improve the cascade of TB care by improving early detection and finding people with TB who are missed by national programs, thereby reducing patient delays and improving treatment success rates through intensive patient support and follow-up. To improve access to key and vulnerable populations and address access barriers (gender, financial, and human rights), country partners have prioritized collecting evidence on current barriers to find people with TB, along with comprehensive analysis of data on underserved populations that may be left behind.

With COVID-19, individuals and communities are facing a turning point. The pandemic is reversing hard-won gains in TB responses in our countries, taking us back to where we were 10 years ago. Because frontline workers are busy with COVID-19 (and are themselves becoming unwell with the disease), many people with TB have remained undiagnosed, developed advanced forms of disease, and transmitted the disease to their households. As we speak, tens of thousands of people with TB are coughing, sweating, and losing weight, and may be passing TB on to the people with whom they live. In only the last 6 months, the number of people with TB identified in the region has dropped by almost half. This trend is likely to continue unless we act quickly.

Being agile in times of uncertainty and finding new ways to work has become the mantra of our TB REP 2.0 team. Part of the new normal is counting not only the losses, but also the gains. COVID-19 has accelerated the shift to people-centered services, including diversification in treatment modalities: home-based directly observed therapy (DOT) and digital adherence have become a reality for so many people. Another positive side-effect is the increased prominence of civil society organizations as tangible additional resources for health care workers. I hope this is a point of no return and that we can keep this major gain even after the pandemic has ended. However, while national programs struggle with case finding, the role of civil society remains too small. We still urgently need to prioritize the engagement of civil society in assessing gender, financial, human rights, and other social barriers (including stigma and discrimination) to accessing TB services.

In this context, I am pleased that the regional report *Breaking the Silence: Human Rights, Gender, Stigma and Discrimination Barriers to TB Services in Georgia, Kazakhstan, Kyrgyzstan, Tajikistan and Ukraine*, is a timely resource to inform ways of addressing these structural barriers, so that the most vulnerable people are not left behind. It provides a crisp overview of several reports of communities, rights, and gender (CRG) assessments and reviews. The majority of reports are based on Stop TB Partnership tools to assist countries in transforming the TB response to be equitable, rights-based, gender-transformative, people-centered, and compliant with investment packages to strengthen national TB policies and funding applications to the Global Fund. It presents differentiated findings on stigma and discrimination, gender, financial barriers, and human rights and proposes specific ways forward in each of these domains. The report contributes to the growing body of evidence to inform appropriate action aligned to those recommended in the Global Fund's *Technical Brief on Tuberculosis, Gender and Human Rights (2020)* and *COVID-19 Information Note: "Catch-up" Plans to Mitigate the Impact of COVID-19 on TB Services*. The report calls for a comprehensive approach to scale-up and hasten the 'translation' of understanding about CRG issues into updated policies and funded programs.



Stela BIVOL
PAS Center Director

Executive Summary

This is an overview based on several reports of communities, rights, and gender (CRG) assessments and reviews from five Eastern Europe/Central Asia (EECA) countries: Georgia, Kazakhstan, Kyrgyzstan, Tajikistan, and Ukraine. The overview briefly summarizes the situation of key populations, gender, human rights, and stigma as they relate to tuberculosis (TB) in each country, followed by an in-depth discussion of common bottlenecks and solutions.

Assessments implemented by national civil society organizations (CSOs) and supported by the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund) through the regional program on advancing people-centered quality TB care (TB-REP 2.0) went through multi-stakeholder prioritization processes, evaluating epidemiological data and a number of risk factors to form a short-list of key populations. For example, stakeholders in Georgia prioritized people who use drugs, internally displaced persons, and persons with a history of imprisonment, whereas Kazakhstan stakeholders prioritized internal migrants and people living with HIV. The implementing CSOs subsequently engaged key populations in qualitative information collection relevant to their setting.

The information reviewed suggests that people who use drugs and people with a history of imprisonment, especially women from these key populations, are the most vulnerable and stigmatized. People who use drugs have difficulties accessing services because of their criminalization, and people with a history of imprisonment encounter barriers when they do not have a national ID or a passport (which can occur following imprisonment) or when they do not have a domicile registration. The proposed solutions include improving service integration, including co-locating opioid substitution, HIV, and TB services in the location where access is the easiest and task-shifting to CSOs that already work with specific key populations. CSOs may need additional training in, for example, case management, multi-disciplinary approaches to TB care, and effective ways to address human rights, gender, and stigma as part of TB care. Improved service comprehensiveness can be achieved through using peer educators, multidisciplinary teams (MDTs), providing training for police and prison staff, and introducing human rights into the curricula of relevant pre-service training institutions. Another intervention is to increase awareness among the key populations about the rights and responsibilities of people with TB.

In all countries covered by the overview, women have less economic resources, which restricts their access to care and impedes their ability to be diagnosed on time. Women also tend to delay health seeking because of the workload in their household. In addition, reports from the three Central Asian countries (Kazakhstan, Kyrgyzstan, and Tajikistan) discuss gender-based violence (GBV) towards women with TB, divorce, and women being

separated from their children as a result of a TB diagnosis. For men, access to diagnosis and treatment adherence are hampered by their role as breadwinners, fears of loss of income, and the inconvenience of directly observed therapy (DOT). Job security is a special area of attention discussed in this overview. Transgender people's participation in the assessments was limited. Proposed solutions begin with disaggregating all indicators into men, women and others, including but not limited to drug-resistant (DR)-TB, TB/HIV, and TB treatment outcomes such as mortality or loss to follow up. This will help to monitor programs and to design appropriate gender-responsive interventions. A 'family approach' to supporting people with TB is also recommended, which involves engaging a partner and other family members in counseling to address myths, identify potential barriers to adherence, and prevent violence. Other activities to prevent and address GBV include training treatment supporters and MDTs in recognizing and supporting someone who is living with an abusive partner or family member and linking GBV survivors to medical and legal services.

In the area of stigma, two types appear particularly important: stigma by health care workers, especially towards key populations with TB, and stigma from the general community in small rural areas. The latter is often linked to breaches of confidentiality of the diagnosis and through cumbersome contact investigation practices. Discriminatory attitudes, lack of training, and engagement of primary health care staff seem to be important obstacles, particularly in implementing ambulatory models of TB care. At the same time, many countries identify health care workers as a high-risk population because they have an increased risk of TB infection, but compensation schemes for health care workers are not always adequate and there may be insufficient protection of workers' rights. In high stigma working environments, health care workers who become ill with TB prefer to self-treat or otherwise bypass the system because of the negative attitudes from supervisors and colleagues. Addressing stigma and discrimination by health care workers needs to start with improving their working conditions, including infection prevention and control, developing and implementing strict and clear protocols regarding confidentiality, and, where necessary, intervening to change workplace culture and policies. These should be coupled with training health care workers to better understand key populations, gender, tolerance, human rights, and patients' rights and including these topics into the curricula of pre-service, post-graduate, and continuous education.

People with TB may face a variety of social conditions that require a tailored set of interventions. The overview discusses service integration, links to social services, case management, MDTs, contact investigation, provision of more than one option for treatment administration and support, and offering counseling as a part of people-centered care. The overview also discusses a more meaningful role for primary health care workers, for instance by participating in case management and helping the most vulnerable navigate the

health and social security systems.

Case managers do not necessarily have to be medical workers, they can be trained lay persons, such as CSO staff members or peer educators. Non-governmental stakeholders engaged in service provision need to be included in supportive supervision by national TB programs to ensure quality of services and knowledge sharing. Beyond service provision, civil society actors are encouraged to spearhead community-led monitoring and rights advocacy. These watchdog functions need to be backed by appropriate funding. The limited implementation capacity of CSOs is a concern and capacity needs to be developed and scaled up to match implementation requirements. A few interventions to strengthen community systems are discussed in this overview.

Across the countries included, this overview found inequities in how different patient groups accessed and remained in TB care, and that the consequences of TB were more catastrophic to some population groups than to others. Multi-stakeholder processes were helpful to build the necessary consensus between people with TB, CSOs, governmental service providers, and those ensuring oversight. The growing body of information on the role of key populations, gender, human rights, stigma, and discrimination in TB in EECA is providing the necessary evidence to inform actions. A summary of barriers, key findings, and potential solutions is provided in Table 1.

While the focus of this regional overview is on synthesizing common barriers and potential solutions, it is by its nature cross-sectional and it does not analyze initiated or ongoing initiatives to reduce these barriers in countries. Overall countries are making progress in reforming their TB care and moving towards more coordinated people-centered care models tailored to the needs of most vulnerable and hard to reach populations. Such good practices, ranging from social contracting to serve key populations to counteracting discrimination, introducing gender-responsive interventions, and case-management and navigation, are being programmed and rolled out in the region. These cases should be documented and shared through additional regional efforts.

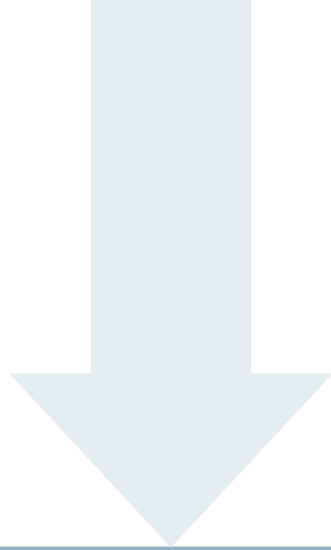
Table 1.

Summary of identified common barriers to providing TB care, key findings, and potential solutions

Common barrier: Extreme discrimination against some key populations	
Key findings	Solutions
<ul style="list-style-type: none">• PWUD and people with a history of imprisonment, especially women from these key populations, appear to be the most vulnerable and stigmatized• PWUD have difficulties accessing services because of their criminalization• People with a history of imprisonment encounter barriers when they do not have a national ID or a domicile registration	<p>Improving service integration</p> <ul style="list-style-type: none">• Co-locating opioid substitution, HIV, and TB services in the lowest threshold setting• Task-shifting to NGOs that already work with specific key populations <p>Improving service comprehensiveness</p> <ul style="list-style-type: none">• Inclusion of peer educators• Multidisciplinary teams <p>Training for police and prison staff</p> <ul style="list-style-type: none">• Including TB-relevant information into ongoing activities of the HIV program on human rights and law enforcement• Introducing human rights into the curriculum of pre-service police training institutions <p>Improving the rights awareness of key populations</p> <ul style="list-style-type: none">• Training and awareness building on the rights and responsibilities of people with TB

Common barrier:
Consequences of TB for women

Key findings	Solutions
<ul style="list-style-type: none"> • Women have to overcome barriers such as scarce finances, lack of family support, and GBV related to TB • Women carry the burden of unpaid household work and limited childcare options • Women lack decision-making power over finances, which leads to downgrade of women's health needs, delaying TB diagnosis and/or treatment • Self-stigma is higher in women • Women face catastrophic consequences of TB 	<p>Disaggregate data</p> <ul style="list-style-type: none"> • Disaggregating all indicators into men, women and others will help monitor programs and design appropriate gender-responsive interventions <p>TB and pregnancy, and breastfeeding</p> <ul style="list-style-type: none"> • Provide counseling on family planning • Advise pregnant women on the risks related to treatment • Provide information and assistance to breastfeeding women with TB <p>Family approach to supporting people with TB</p> <ul style="list-style-type: none"> • addressing myths, identifying potential barriers to adherence, and preventing violence <p>Addressing GBV</p> <ul style="list-style-type: none"> • Training treatment supporters and MDTs in recognizing and support someone who is living with an abusive partner or family member • Linking GBV survivors to medical and legal services • Educating the management and the employees of the shelters about TB and how to support GBV survivors with TB



Common barrier:
Stigmatization by HCWs

Key findings	Solutions
<ul style="list-style-type: none">• Lack of, or breaches of confidentiality, and discrimination by HCWs• Stigmatization of HCWs with TB, lack of infection prevention and control	<p>Addressing stigma and discrimination</p> <ul style="list-style-type: none">• Improving working conditions, including prevention and infection control• Developing and implementing strict and clear protocols regarding confidentiality• Training HCWs on key populations, gender, tolerance, human rights, and patients' rights

Common barrier:
Lack of people-centeredness

Key findings	Solutions
<ul style="list-style-type: none"> • Lack of childcare provisions affects women’s ability to attend facility-based DOT • COVID-19 is making it harder to receive DOT • In some rural and remote places, DOT is not and has never been available 	<p>Case management</p> <ul style="list-style-type: none"> • Developing TB case management guidelines and training case managers • Selecting case managers with a client-oriented mindset to help the most vulnerable navigate the health, and social security systems • Identifying patients to whom regular support will not be sufficient and engaging them in enhanced support by MDTs <p>Confidentiality and contact investigation</p> <ul style="list-style-type: none"> • Case manager building rapport with the patient and explaining the importance of contact investigation, underlining the confidentiality of a patient’s diagnosis, and motivating the people with TB to provide the relevant contacts. <p>Treatment support options</p> <ul style="list-style-type: none"> • Providing a range of alternatives such as clinic-based DOT, community-based DOT, multi-week dispensing, and Video-supported Treatment (VST) • Discussing the choice of treatment provider at the intake with each new TB patient and allowing this to be revised <p>Counseling, mental health, and self-stigma</p> <ul style="list-style-type: none"> • Making psychological care available for TB patients at all stages of diagnosis and treatment, including online counseling for people whose ability to come to the health care provider is limited • Engaging NGOs to train and deploy peer educators and treatment supporters

Background

In the political declaration on the fight against tuberculosis, approved by the High Level Meeting of the General Assembly in September 2018, the Heads and representatives of States and Governments committed to “protect and promote equity, ethics, gender equality and human rights in addressing tuberculosis”.¹ The Declaration of the rights of people affected by tuberculosis (TB), developed in the aftermath of the United Nations High Level Meeting, reiterates the rights of people affected by TB and the obligation of the State to respect, protect and fulfill these rights.² In this context of an increasing shift away from limiting TB response to medical interventions, the Global Fund to Fight AIDS, TB and malaria continues to support the eligible countries’ efforts to design and implement programs that are based on human rights, strive to engage the TB affected communities, promote gender-responsive interventions and combat stigma.

A multicountry Global Fund-supported grant on advancing people-centered quality TB care – from the new model of care towards improving drug-resistant (DR)-TB early detection and treatment outcomes or TB-REP 2.0 commenced in 2019. The program’s first objective is to ensure full engagement of communities and civil society in TB prevention and care for improving TB and DR-TB case detection and patient care outcomes. The second objective is to strengthen the health systems to enable integrated patient-centered TB and DR-TB care delivery while addressing the needs of key populations. TB-REP 2.0 is a multi-partner program, implemented by the PAS Center, as the principal recipient in collaboration with the World Health Organisation (WHO) Regional Office for Europe, TB Europe Coalition, TBpeople and Global TB Caucus.

One of TB-REP 2.0 intervention areas is collecting evidence on the barriers to finding people with TB who are missed by the programs and have challenges in accessing care. Civil society-led communities, rights and gender (CRG) assessments, part of TB-REP 2.0 interventions, help generate such evidence and facilitate multi-stakeholder participation in removing the identified barriers. These assessments provide an important baseline of the situation of TB key populations, the state of human rights, gender related issues and the extent of stigma - factors that directly contribute to a TB programs’ success or failure to reach the most vulnerable people affected by TB.

TBC Consult was commissioned to prepare this overview report in order to identify any common barriers and solutions. The overview summarizes and analyses the results of several assessments conducted in Eastern Europe/Central Asia (EECA). The countries with available CRG reports are Georgia, Kazakhstan, Kyrgyzstan, Tajikistan and Ukraine.

Methods

The TBC Consult team conducted a desk review of a total of nine reports. Some of the countries had more than one assessment that touched upon key populations, human rights, legal, stigma and/or gender aspects in TB. Two of the assessments have been supported as part of TB-REP 2.0 by PAS Center and seven were facilitated by the Stop TB Partnership or Global Fund directly. All reports were based on qualitative data, collected through interviews and/or focus group discussions, and triangulated against information collected through literature reviews. The assessments can be grouped as follows:

1. Early assessments: are those conducted in 2016 before the TB gender assessment tool and the TB legal environment assessment tool were finalized by the Stop TB Partnership;
2. Assessments (Ukraine legal and Ukraine key populations and gender) that were conducted using Stop TB Partnership tools^a;
3. “Scaling up Programs to Reduce Human Rights Related Barriers to HIV and TB Services” baseline assessments that have been conducted as part of “Breaking down Barriers”^b initiative.
4. Assessments using an integrated CRG toolkit developed by the Stop TB Partnership in 2019.³

Methods of the early assessments did not focus on stakeholder consensus building around the findings or joint action planning. TB assessments in Ukraine, conducted before the integrated CRG toolkit was developed, had some thematic overlaps but were carried out independently of each other. Baseline assessments for “Breaking down Barriers” combined TB and HIV and did not always aim at a validation and action planning by in-country stakeholders. Based on lessons learnt, the integrated CRG toolkit made provisions to combine and harmonize different parts of the assessment and to emphasize a process of engagement for national multi-stakeholders.

Table 2 lists the organizations that led and supported the assessments, the type of the assessment, its coverage, and the year of publication.

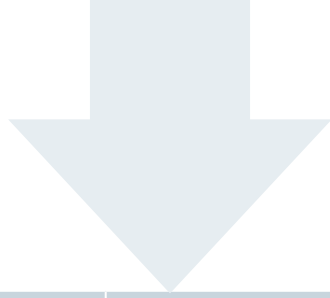
^a Individual tools developed by the Stop TB Partnership, e.g. TB stigma assessment, gender assessment, TB gender investment package and others can be found at <http://www.stoptb.org/communities/%20.stoptb.org/communities/>. These and other tools were developed to assist countries in transforming their TB response policies, strategies and interventions to be rights-based, gender-responsive, and reach populations most at risk.

^b Through the “Breaking Down Barriers” the Global Fund provides support to scale up evidence-based programming and reduce barriers related to human rights across HIV, TB and malaria services. Kyrgyzstan and Ukraine are two Eastern Europe/Central Asia (EECA) countries that are among the 20 countries supported through the initiative.

Table 2.
Summary of the analyzed EECA assessment reports

Country	Lead organization	Type of assessment and title	Coverage	Year
Georgia	New Vector/ PAS Center	TB CRG assessment “Assessment of CRG barriers for TB high-risk groups in Georgia”	Tbilisi, Rustavi, Gori, Batumi, Zugdidi	2020
Kazakhstan	Kazakh Union of People Living with HIV (PLHIV)/PAS Center	TB CRG assessment “Assessment of legal, gender, stigma and human rights barriers to key populations in TB response in Almaty and Almaty Oblast” ^c	Almaty, Almaty Oblast	2020
Kyrgyzstan	TB Coalition/ Stop TB Partnership	TB gender assessment in Kyrgyzstan	Bishkek, Chui Oblast	2016
	TB Coalition/ Stop TB Partnership	Legal Review. Tuberculosis in Kyrgyzstan	Bishkek, Chui Oblast	2016
	The Global Fund / APMG Health	Scaling up Programs to Reduce Human Rights Related Barriers to HIV and	Bishkek, Chui Oblast, Osh and Jalalabad	2018

^c Oblast is a unit of administrative division, comparable to a province.



Tajikistan	NGO “Gender and Development”/ The Global Fund/Canadian Legal Network	Legal, gender, and stigma barriers to TB services in Tajikistan	National	2020
Ukraine	Alliance for Public Health/ Stop TB Partnership	Communities, rights and gender TB tools assessments (key populations and gender)	Kyiv, Mykolaiv, Odesa, Lviv provinces	2018
	United Nations Development Programme, Stop TB Partnership	Report on the legal environment assessment for TB in Ukraine	Kyiv, Rivne, Mykolaiv, Donetsk and Luhansk (areas controlled by the government), Dnipro and Chernihiv	2018
	The Global Fund / APMG Health	Scaling up Programs to Reduce Human Rights Related Barriers to HIV and TB Services	Kyiv, Odessa, Dnipro, Zaporizhya, Kramatorsk and Mykolaiv	2018

National strategic plans and Global Fund funding requests were also reviewed by the TBC Consult team when applicable and available. The reports were analyzed using MAXQDA software by a team of two researchers, who pre-established the codes that were assigned to the documents’ segments.

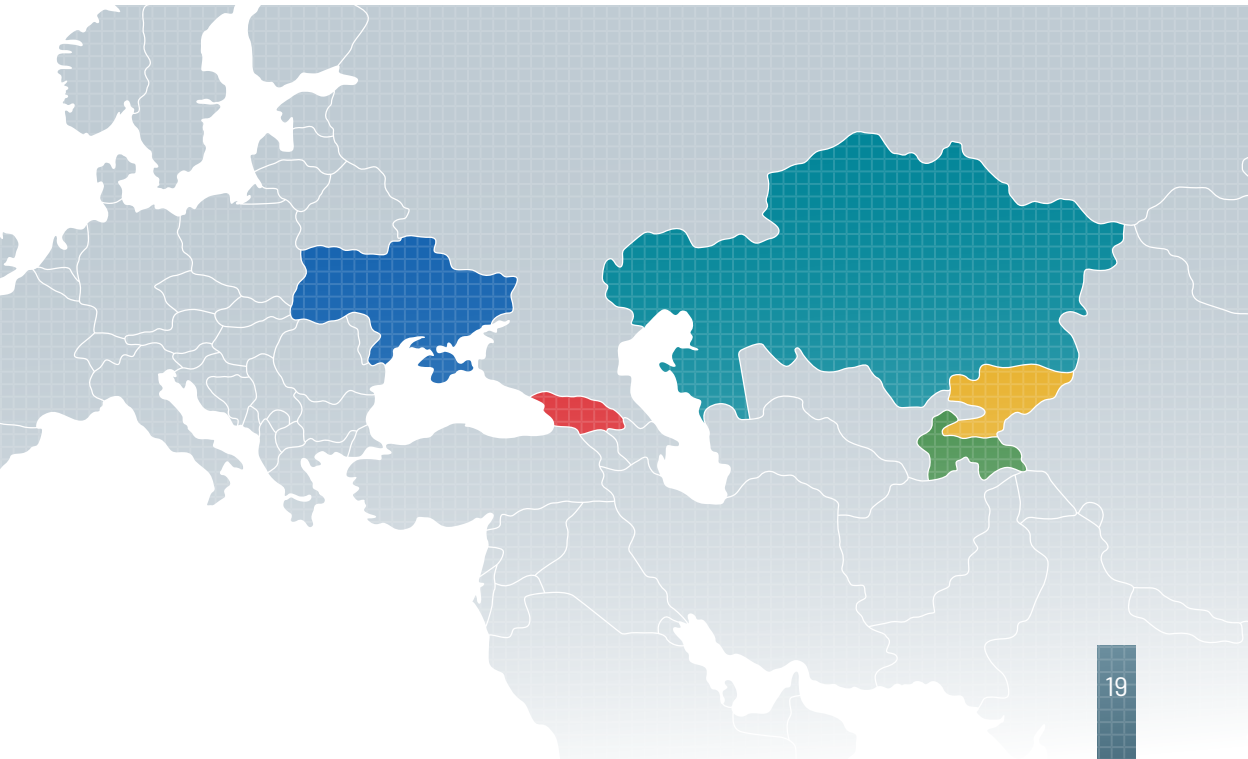
The other countries in EECA did not have TB CRG-related assessments that could be identified through searching the individual countries’ dashboards on the Stop TB Partnership website or on the Global Fund website.

Summaries of results per country

This chapter presents a summary of each country based on one or more CRG reports. To contextualize the CRG information, each summary starts with the most current general TB information, including estimated incidence, information about TB notification, disaggregated by sex, availability of bacteriological confirmation and treatment success rates. Each summary includes TB and gender barriers, human rights and legal considerations and any stigma and discrimination barriers.

Key populations are listed as they are reflected in the national strategies. In some cases assessments prioritized a sub-set of key populations, in order to have manageable numbers of respondents and collect detailed information, while focusing on the most marginalized groups, especially if data about TB in these groups were largely unavailable. For instance, in Georgia and Kazakhstan, the TB-REP 2.0 project included multi-stakeholder workshops.

These multi-stakeholder events were used to broaden the participation of actors, including key populations, and engage them in a prioritization. The prioritization followed an approach described in “Data for Action for Tuberculosis Key, Vulnerable and Underserved Populations”⁴, which included a systematic consideration for all possible key populations in the country, their estimated contribution to the national TB burden, and their environmental, biological, behavioral, economic, legal, human rights and gender barriers. Besides, multi-stakeholders were engaged in endorsement of the assessments’ methods and tools, and subsequently in a validation of findings and the development of recommendations and actions.





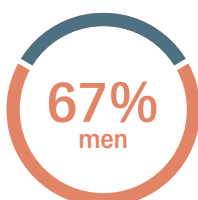
GEORGIA

In 2019, according to WHO

total estimated
TB incidence

74
peoples
per **100 000** population

2 169
new and
relapsed cases
were notified



The percentage of
bacteriological confirmation
among new cases was very high

99%

Treatment success
rate was

84%

among new and relapse cases
registered in 2018

62%

among previously treated cases, excluding
relapse, registered in the same year

64%

for Multi Drug-Resistant (MDR)/
Rifampicin Resistant (RR)-TB cases
started on second-line treatment in
2017^d

^d Accessed at https://worldhealthorg.shinyapps.io/tb_profiles/?_inputs_&lan=%22EN%22&iso2=%22GE%22 November 19, 2020

Key populations

National Strategy for Tuberculosis Control in Georgia (2019-2022) identifies a fairly large part of the population at a higher risk of TB and prioritizes them for systematic TB screenings. The group includes contacts, PLHIV, persons detained in penitentiary institutions, people with selected medical conditions and “other sub-populations”. These sub-populations include “homeless people, people living in remote mountainous areas, migrants and other vulnerable groups”.⁵ The strategy further speaks about community-based screening, including door-to-door visits and screenings in e.g. shelters; it underlines the role of non-governmental organizations (NGOs) in a people-centered approach and advocacy for human rights of vulnerable populations.

The three populations prioritized by multi-stakeholders for the CRG assessment in Georgia were people who use drugs, persons with a history of imprisonment, and internally displaced persons (IDP). Illicit drug use is a criminal offence in Georgia and people who use drugs, especially those outside of the Opioid Substitution Therapy (OST) are hesitant to contact health providers because of fears of exposure and prosecution. OST is available in Georgia, which includes penitentiaries. Specific barriers to people who use drugs in relation to TB include difficulties in adherence and, for those enrolled in OST, the inconvenience of coming to a Directly Observed Therapy (DOT) facility for observed treatment. Access to Video-supported Treatment (VST) by the key populations was not discussed in the CRG report. Although VST has been in use since December 2017²⁵, the respondents neither knew about VST nor been offered it.

There is regular chest X-ray screening in prisons and pre-trial facilities and the new and repurposed anti-TB medicines are available. In 2017, TB cases among prisoners accounted for 2.8% of all new and relapse TB cases in Georgia.⁵ TB rates of the prison population were not available in the CRG assessment report. There is also a lack of information about TB among people with a history of imprisonment, such information is usually not available. According to the assessment, respondents with a history of imprisonment were often people who use drugs, and thus their barriers were similar.

The health authorities of Abkhazia reported that there were 241 900 IDPs, including 61 168 children, from Abkhazia in 2018.⁵ Rates of TB among IDPs were not available. The CRG assessment report points out that the main barriers for IDPs seeking TB diagnosis and treatment were remoteness of facilities and/or a lack of confidence that the local facilities could provide a reliable diagnosis, fear of losing employment and fear of stigmatization from the communities they live in. Since free healthcare services are only available in the place of residence, IDPs who seek confirmation of their TB diagnosis outside of their place of residence may have to pay for it.

Gender

The current Strategy for Tuberculosis Control in Georgia (2019-2022) is silent about gender, and any indicators or barriers related to gender in TB. The CRG assessment found that women are more likely to deprioritize health seeking than men, often because of unavailability of child care. Women, especially in rural areas and in IDP communities, have limited power over family budgets, which may be linked with delaying diagnosis due to challenges in covering out-of-pocket payments. Women appeared to have less information about TB compared to men, especially about where to turn to in case of symptoms. Compared to men, women experience less family support during their treatment. A diagnosis of TB may be more serious for women due to a consequential divorce and not being able to see their children.

Men report more psychological challenges than women, such as feeling useless and suicidal. TB mortality in men is higher than women, according to the National TB Program. There is almost no information about TB in trans* persons, although from secondary data the CRG report captured one instance of derogatory attitude by health care workers.⁵

Human rights

There were several types of human rights violations identified by the CRG assessment. The right to education was hindered when the children of people with TB would not be admitted to school, kindergarten and people with TB could not attend university. There were instances of violating the right to health by denying service. The right to privacy was impeded by a requirement to report one's history of TB to be hired for some government jobs, while such health reports are not required by law. There were delays in receiving treatment support incentives and instances when social security payments would be cancelled because a person with TB's income increases as a result of receiving a TB incentive. Some respondents reported inadequate conditions inside TB facilities and discriminatory attitudes to socially vulnerable people and people coming from rural areas.⁵

The CRG assessment report points out an important barrier, encountered at the Primary Health Care (PHC). As perceived by people with TB, family physicians let them undergo various paid tests conducted at their PHC practice, before suspecting TB and referring them to free TB testing. This contributed to delays of diagnosis and the financial burden of TB.⁵

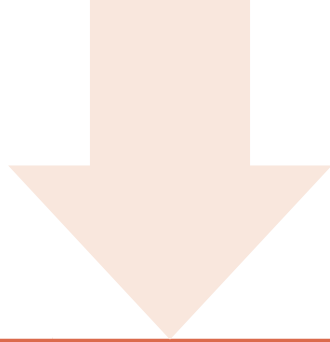
Stigma

The CRG assessment found that persons diagnosed with TB are afraid it will worsen their relationship with family members. They are also afraid of losing their jobs. There is self-stigma among people with TB. The prevailing attitude towards TB in the general population is negative: people often associate TB with using drugs or having been in a prison. According

to the assessment, stigmatization can result from members of the community seeing DOT nurses delivering medication to the patients' homes. There is also a lack of trust: people with TB fear that they are subjects of testing experimental medicines.⁵

Summary of CRG barriers in Georgia

Key populations prioritized for the assessment	Specific challenges in relation to TB	Estimated size of the population
People who use drugs (PWUD)	Fear of exposure and prosecution	Not available
People with a history of imprisonment	No specific information	Not available
IDP	<ul style="list-style-type: none"> • Remoteness of facilities and/or lack of confidence that the local facilities provide a reliable diagnosis • Fear of losing employment • Fear of stigmatization • Financial barriers 	241 900 ⁵
Gender barriers		
Women	Men	Other
<ul style="list-style-type: none"> • Unavailability of child care • Limited power over family budgets • Little information about TB • Divorce / not being able to see children 	Psychological challenges, such as feeling useless and suicidal	Derogatory attitude by health care workers



Human rights or legal concerns

- Right to work
- Right to education
- Right to privacy

Stigma/discrimination barriers

- Fears of losing jobs
- Fears of stigma from family
- Self-stigma

Other barriers

- Unnecessary paid tests at PHC
- Complications with treatment monetary incentives that resulted in patients losing payments from social security
- Geographic access



KAZAKHSTAN

In 2019, according to WHO

total estimated
TB incidence

68

peoples

per **100 000** population

13 000

new and
relapsed cases

were notified

The percentage of
bacteriological confirmation
among new cases was very high

98%

Treatment success
rate was

90%

among new and relapse cases
registered in 2018

75%

among previously treated cases, excluding
relapse, registered in the same year



People with MDR/RR-TB
who started second-line treatment
in 2017 had a treatment success rate of

81%^e

^e Accessed at https://worldhealthorg.shinyapps.io/tb_profiles/?_inputs_&lan=%22EN%22&iso2=%22KZ%22 on 19 November 2020

Key populations

The Complex Plan for Tuberculosis Control in Kazakhstan (2014-2020) refers to such vulnerable populations as people living with HIV, alcohol-dependent persons, people who use drugs, homeless people, prisoners and others⁶ and a few key populations are mentioned across a number of other legal and regulatory documents.⁷ The CRG assessment by Kazakhstan Union of people living with HIV identified that in 2017 the rate of TB disease in prisoners in Kazakhstan was 2 015 per 100 000 prisoners, and in the same year there were 734 notified people living with HIV, while the information about TB in such groups as people who use drugs, the homeless and migrants is lacking.⁷

The multi-stakeholders, convened by the Kazakhstan Union of people living with HIV and the National TB Program, prioritized two groups for the CRG assessment: people living with HIV and internal migrants. The assessment showed several barriers faced by these two key populations. Internal migrants often encountered housing issues, e.g. eviction as a result of TB diagnosis becoming known by the house owner. Their lack of job security led to delaying diagnosis. Diagnostic procedures at the PHC took a disproportionately long time according to internal migrants. Chances of finding work after TB treatment for internal migrants were limited. People living with HIV encountered delays with correct diagnosis because of a lack of awareness among PHC about HIV/TB. People living with HIV experienced the most barriers to treatment adherence and continuation. These included a lack of social support services and the treatment of side effects. Both key populations mentioned a lack of people-centered approach, which could offer more convenience of DOT delivery.⁷

Gender

CRG assessment respondents mentioned that women, and particularly women from key populations, were more often stigmatized and discriminated. Women especially with small children would delay diagnosis because of a lack of child care. There were instances of women quitting treatment due to pressure from their husbands/partners or from families. The CRG report's observation was that men in general tend to delay TB diagnosis or try to self-treat because of a lack of job security. Alcohol or drug dependencies, which men struggle with more often than women, result in TB treatment adherence challenges.⁷

Human rights

Among the legal barriers indicated by TB patients were difficulties of domicile registration needed to access PHC facilities. The problem with domicile registration concerns only PHCs. At TB dispensary, patients could receive medical services without delay, and without identification documents. There is limited awareness about availability of social support

and medical staff usually do not provide patients with such information. Those patients who attempted accessing social support, found the process very bureaucratic. The absence of one of the many required documents could be grounds for refusal. Rural population faces barriers due to long distances to district hospitals. Internal migrants struggle with lengthy re-registration in order to access primary health care.⁷

Outpatient treatment does not yet imply that the TB program has fully transitioned to a people-centered approach. Due to the time and travel for facility-based DOT, patients reported running risks of losing their jobs, being expelled from a university, or having family problems. Patients indicated a lack of qualified psychological assistance at all stages of treatment. The CRG assessment report also points out that the respondents were not aware of and were not offered a possibility to use VST⁷. Although the rollout of VST in Kazakhstan was in early June 2020, VST options were already available before.

TB patients noted that in most cases family doctors are not trained to suspect TB. The patient has to make significant efforts to get a diagnosis. Also, TB patients indicated that some PHC facilities are not interested in registering TB cases, because this will negatively impact their health statistics and result in penalties from the Healthcare Department. There is a lack of side effects treatment in PHC facilities.⁷

Stigma

According to the CRG assessment report, feelings of shame, fear and guilt caused by self-stigma are key barriers to seeking care, and lead to their delayed diagnosis. Lack of psychological assistance and support from patients' immediate surrounding worsen the situation.⁷

In PHC facilities there is stigma against people with TB, especially key populations and particularly women from key populations. This is expressed by negative attitudes, disclosure of the diagnosis, and refusal to provide services. There is also the issue of stigma and discrimination at the work place by employers who look for any reason to lay off a person with TB. Dismissal could also be triggered by being late to work or missing a work shift when people with TB must attend DOT. Another issue is the lack of knowledge of patients' rights and the inability of TB patients to protect themselves in cases of discrimination.⁷

Summary of CRG barriers in Kazakhstan

Key populations prioritized for the assessment	Specific challenges in relation to TB	Estimated size of the population
PLHIV	<ul style="list-style-type: none"> • Delays with correct diagnosis • Lack of social support services • Difficulty coping with treatment side effects 	26 000 (22 000 - 30 000) ^f
Internal migrants	<ul style="list-style-type: none"> • Loss of rented housing as a result of TB diagnosis • Lack of job security 	Not available
Gender barriers		
Women	Men	Other
<ul style="list-style-type: none"> • More stigmatized and discriminated, particularly if from key populations • Unavailability of child care • Pressure from husbands/partners or from families to discontinue treatment 	<ul style="list-style-type: none"> • Lack of job security • Alcohol or drug dependencies hamper adherence 	No information

^f According to <https://www.unaids.org/en/regionscountries/countries/kazakhstan> accessed on 16 June 2020



Human rights or legal concerns

- Difficulties of domicile registration
- Right to work
- Right to education
- Right to privacy
- Access to social support and access to information about availability of social support
- Reproductive rights of pregnant women with TB

Stigma/discrimination barriers

- Stigma and discrimination at the work place
- Self-stigma

Other barriers

- Lack of qualified psychological assistance
- Lack of knowledge on patients' rights



KYRGYZSTAN

In 2019, according to WHO

estimated
TB incidence

110
peoples

per **100 000** population

7 100
new and
relapsed cases
were notified

Percentage of bacteriological
confirmation among new cases
was high

93%

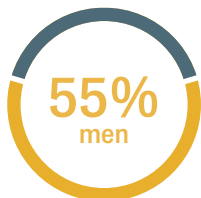
Treatment success
rate was

81%

among new relapse cases registered
in 2019

51%

among previously treated cases,
excluding relapse, registered in 2018



MDR/RR-TB patients who started
second-line treatment in 2017 had a

55%

treatment success rate⁸

⁸ Accessed at https://worldhealthorg.shinyapps.io/tb_profiles/?_inputs_&lan=%22EN%22&iso2=%22KG%22 on 19 November 2020

Key populations

Key TB populations in Kyrgyzstan are people who use drugs, prisoners and internal migrants⁸. Migrants and people with a history of imprisonment struggle with access to health care to continue their treatment because of a lack of domicile registration or a passport^{8,9}. Externally funded training for prison staff on TB, which was no longer provided at the time of the baseline assessment, had a positive contribution on the staff attitudes towards prisoners with TB.⁸ The assessment explains that in recent years there are restrictions to peer programs in prisons. According to the same report “the TB key populations that are most stigmatized in the health system are people who inject drugs, particularly those who have a history of imprisonment, and women who inject drugs”, especially if they are pregnant.⁸

Lack of OST in some TB facilities is a barrier to adherence of people who use drugs. Some people who use drugs were asked by hospital staff to stop OST while on TB treatment because they did “not want to deal with the medicine that require special storage”.⁸

Access to health care in rural areas is made complicated by stigma and the need to make out-of-pocket payments.

Another important key population which experiences a lot of stigma, including stigma in healthcare institutions, is homeless people.⁹

In order to avoid TB testing, labor migrants immigrate to other countries illegally. Illegal immigration hampers their access to medical care in the host country.

Gender

Women with TB are subjected to physical, emotional and sexual violence because of their disease. Having limited decision-making power over money, women delay diagnosis due to the perception that it may cost a lot for the family budget. Women with TB were more likely to self-stigmatize because of a limited knowledge about TB transmission. During drug resistant TB treatment, pregnant women were advised to abort their pregnancies. Men delay health care seeking, which is often related to being the only breadwinner for the family.⁹

Human rights

There are several regulations and policies which contribute to legal barriers for TB patients in Kyrgyzstan. Patients have a lack of information about their rights and a lack of access to legal services. Patients are not aware of their right to social support and free legal assistance, nor about a right to housing, applicable in some cases. Making patients aware of which drugs and services are free, could help them avoid illegitimate out-of-pocket payments.¹⁰

Similar to the other countries, financial problems arise from the violation of the right to work and compensation during sick leave. A lack of flexibility in DOT provision resulted in problems with employment. According to the “Law on the Protection of the Population Against Tuberculosis” there is a list of professions which are prohibited for TB patients. Most of the people with TB who were unemployed were unsure about their chances of future employment.¹⁰

According to the Kyrgyz Criminal Code “compulsory TB treatment for prisoners can be implemented”.⁸ However, similar to Kazakhstan where such law exists, there were no accounts of this law’s practical application.

The contacts investigation policy and practice, used at the time of the legal review, did not respect patients’ rights to privacy: a patient’s contacts could be reached out to without informing the patient. This produced a counter action: patients would not disclose information about their close contacts, such as co-workers, and thus contacts who may have been infected would be unaware and not be invited for a check up.¹⁰

Stigma

There is an especially high stigma from PHC workers towards key populations in Kyrgyzstan. It is attributed to fear and lack of knowledge about TB transmission. Stigma and a lack of professionalism on the part of health staff make patients travel long distances to receive care from TB facilities instead of from PHC. Myths, misconceptions and stereotypes around TB disease increase stigma from the community and family members as well, this exacerbates the patients’ self-stigma and they try to hide the fact that they have TB. In general, people with MDR-TB are more likely to be stigmatized by healthcare workers and in their community.⁸

Summary of CRG barriers in Kyrgyzstan

Key populations mentioned by the assessments/reviews	Specific challenges in relation to TB	Estimated size of the population
PWUD	Lack of OST	Not available
People with a history of imprisonment	Lack of domicile registration or a passport	Not available
Internal migrants	Lack of domicile registration	Not available



Gender barriers

Women	Men	Other
<ul style="list-style-type: none">• More stigmatized and discriminated, particularly if from key populations• Physical, emotional and sexual violence because of TB disease• Delay diagnosis because of limited financial decision-making power• More likely to self-stigmatize because of a limited knowledge about TB transmission	<p>Delay health care seeking, which is often related to being the only breadwinner for the family</p>	<p>No information</p>

Human rights or legal concerns

- Lack of access to legal services
- People with TB not aware of their right to housing and social support or free legal assistance
- Right to work
- Right to privacy
- Reproductive rights of pregnant women with TB

Stigma/discrimination barriers

- Stigma towards women who inject drugs (especially those who are pregnant)
- Stigma from primary health care workers towards key populations
- Stigma from the community and family members based on misconceptions

Other barriers

- Restrictions to peer programs in prisons
- Lack of professional treatment
- Geographic access
- People with multidrug-resistant TB are more likely to be stigmatized by healthcare workers and their community
- Out-of-pocket payments more frequent in rural areas



TAJIKISTAN

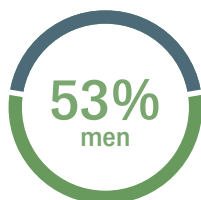
In 2019, according to WHO

total estimated TB incidence

83
peoples

per **100 000** population

7 700
new and
relapsed cases
were notified



There was

100%

of bacteriological confirmation
among the new cases

Treatment success
rate was

89%

among new and relapse cases
registered in 2018

82%

among previously treated cases,
excluding relapse, registered in 2018

People with MDR/RR-TB who started
second-line treatment in 2017 had a
treatment success rate

64%^h

^h Accessed at https://worldhealthorg.shinyapps.io/tb_profiles/?_inputs_&lan=%22EN%22&iso2=%22TJ%22 on 19 November 2020

Key populations

The CRG assessment in Tajikistan prioritized eight key populations, in addition to contacts of persons with TB. People with diabetes and people in military service confirmed few, if any, challenges in relation to accessing TB care. The remaining six key populations were: people with a history of imprisonment, people living with HIV, people who inject drugs, Tajik migrants in Russian Federation, sex workers, PHC and TB facility staff.¹¹

In the past, TB in health care workers was seven times higher compared to the general population.¹² People who use drugs have a higher risk of drug-resistance. While OST is available in Tajikistan, its coverage remains low. There are examples of integration of OST, HIV and TB services although at the scale of only five pilot facilities.¹³ People living with HIV, people who inject drugs, and sex workers mentioned not completely trusting the PHC staff, who often sent them back to HIV and narcology services, instead referring them to the TB service. Tajik migrants do not have access to adequate and affordable health care while in Russian Federation and upon return are not prompted to screen for TB; they appeared unaware of the availability of free TB screening and services. People with a history of imprisonment reported challenges in accessing TB diagnosis while in prison and upon release struggled with access due to a lack of identification (ID), domicile registration and finances.¹¹

Gender

Women's decision-making in relation to health is very limited, especially if they are young and/or have low levels of education. Female-headed households often struggle with poverty. There is fear of divorce for married women while for the unmarried women a TB diagnosis means much worse prospects when finding a partner. TB diagnosis and treatment delay among women is linked to deprioritizing health due to household responsibilities, lack of decision-making and, due to cultural norms, only being able to be attended by female health care providers. It is notable that to address this issue, Dushanbe City TB Center already decided to adjust their hiring so that "more than half of the doctors would be women".

Men's challenges were maintaining employment, while undergoing diagnosis and during treatment, in order to continue providing for the family. Due to masculinity norms in Tajikistan, men's "main function in the family is to protect and bring income".¹¹ Tajik married men who work abroad make money remittances which are usually received not by their wives, but the (male) relatives on the husband's side, which further contributes to women's financial dependence.¹¹

Human rights

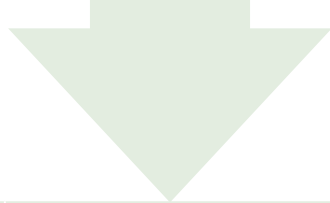
Article 156 of the Health Code of the Republic of Tajikistan lists the rights of people with TB. However, “the Health Code does not prohibit restricting the rights and discrimination of people with TB.” Even though such prohibition exists for people living with HIV in Article 165 of the same Code. Prohibiting restricting the rights of and any discrimination against people with TB could help ensure better access to TB services, especially for key populations.¹¹ TB patients feel insecure about their labor rights and social support, especially if they are employed in the private sector. Patients talked about the difficulty in accessing social support: “only two out of 20 patients interviewed reported receiving any social support”.¹¹ Patients found the social support to be too little. “The Republic of Tajikistan does not have norms establishing a minimum basic level of the right to health, below which the state cannot fall under any circumstances”.¹¹

Stigma

Stigma in Tajikistan, according to the CRG assessment, is primarily based on low public awareness of TB prevention and treatment. Fear of disclosure is very strong. Possibility of job loss or isolation from the family result in delays of TB diagnosis. Society, and in some cases patients themselves, believe that they need to be isolated. Stigma in society adds to the challenge of testing contacts, they do not always want to be registered at PHCs (as TB contacts). Fear and shame that the community will know about one’s diagnosis, are signs of self-stigmatization. Lack of support from their family and friends, negatively influences patients’ adherence to treatment.

Summary of CRG barriers in Tajikistan

Key populations prioritized for the assessment	Specific challenges in relation to TB	Estimated size of the population
People with diabetes and	No specific challenges identified	498.1 per 100 000 population
People in military service	No specific challenges identified	Not available
People with a history of detention	<ul style="list-style-type: none">Challenges in accessing TB diagnosis while in prisonLack of access to health care due to a lack of an ID, domicile registration and poverty	Not available



PLHIV	Not completely trusting the PMC staff	13 000 ¹¹
People who inject drugs (PWID)	Not completely trusting the PMC staff	22 208 ¹¹
Tajik migrants in Russian Federation	<ul style="list-style-type: none"> • Lack of access to adequate and affordable health care while in Russian Federation • Upon return are not prompted to screen for TB • Appear unaware of the availability of free screening and services. 	Approximately 515 000 ¹¹
Sex workers	Not completely trusting the PMC staff	17 591 ¹¹
PHC and TB facility staff	No specific information	Not available

Gender barriers

Women	Men	Other
<ul style="list-style-type: none"> • Limited decision-making • Deprioritizing health due to household responsibilities • Only able to be attended by female health care providers • Fear of divorce / worse prospects of marriage 	Fear of losing employment, while undergoing diagnosis and during treatment	No information

Human rights or legal concerns

- Right to work
- Right to social support

Stigma/discrimination barriers

- Discrimination by employer
- Stigma from family
- Self-stigma

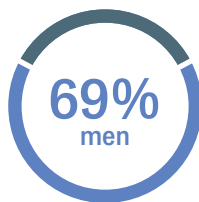
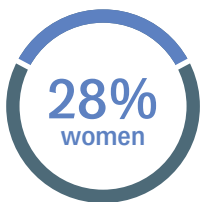


UKRAINE

In 2019, according to WHO

estimated
TB incidence
77
peoples
per **100 000** population

34 000
new and
relapsed cases
were notified



Percentage of bacteriological
confirmation among new cases
was high

97%

Treatment success
rate was

77%

among new and relapse
cases registered in 2018

62%

among previously treated cases, excluding
relapse, registered in 2018

51%

among MDR/RR-TB cases started
on second-line treatment in 2017¹

¹ Accessed at https://worldhealthorg.shinyapps.io/tb_profiles/?_inputs_&lan=%22EN%22&iso2=%22UA%22 on 19 November 2020

Key populations

The “Communities, rights and gender TB tools assessment” team and stakeholders prioritized people living with HIV, prisoners and detainees, people who inject drugs, people with alcohol dependency, homeless people and urban and rural poor as populations based on “epidemiological data, environmental risks, behavioral risks, and legal, economic and social barriers to accessing TB services”.¹⁴ Alcohol dependence, harmful drug use, homelessness, unemployment, prison experience, status of a displaced person are factors that substantially reduce the likelihood of a successful TB treatment completion. Key populations encounter barriers such as a lack of access to counseling and social support, unemployment, and limited services for victims of sexual violence.¹⁴

“Scaling up Programs to Reduce Human Rights Related Barriers to HIV and TB Services” report highlights the absence of a national ID as a barrier to receiving TB services for IDPs, undocumented foreigners and people with a history of imprisonment, while people who use drugs suffer from a lack of services (OST, HIV, TB) integration and from stigma.¹² People who use drugs and people with a history of imprisonment struggle with strong stigma and legal barriers to accessing health, including breaches of their right to confidentiality.^{15,16}

Gender

Generally, women from ethnic minorities, women who have been subjected to gender-based violence, elderly women, women in difficult situations caused by armed conflict, female refugees and women at high risk of HIV have more limited access to health. Women self-stigmatize in relation to TB more than men.¹⁴

Married women’s financial decision-making is limited, they are economically dependent and bear the burden of unpaid work. The situation of Roma women is especially difficult since in addition to the above limitations, from the cultural standpoint they can only use services of female health professionals. Women from key populations may be subjected to stigma and discrimination at health institutions as they appear to have lower levels of knowledge about TB and about their rights. Men on the other hand tend to neglect their health more often compared to women. Their susceptibility and exposure to TB infection are exacerbated by high risk behaviors such as smoking, alcohol dependency and problematic drug use and such factors as labor migration and poor working conditions. The assessment in Ukraine also mentions discrimination of trans* people.¹⁴

Human rights

Social services for TB patients who experience GBV are not available. Women from ethnic minorities, women who were subject to gender-based violence and are in difficult situations

have limited access to healthcare services. There is a lack of social protection of women from rural areas. Transgender people face human rights violations and discriminatory attitude from doctors.¹⁴

Current legislation in Ukraine does not provide guarantees on the protection of labor rights during TB treatment. Moreover, people with TB can be prosecuted and be subjected to involuntary isolation. Students who refused to undergo TB examination, or those who were in contact with people with TB, or did not receive preventive vaccination, could be banned from entering educational facilities. Confidentiality of TB status is not sufficiently regulated, and leads to cases of disclosure without justification.¹⁶

There is a lack of information for patients about their rights: free legal aid and the possibility of receiving outpatients treatment.¹⁶ The healthcare system requires official registration in order to receive free medical care services. This is a barrier for people without documents or those who live far from their official places of residence. Ukrainian policy on drugs continues to be oppressive, which limits access of people who use drugs to healthcare services.¹⁵

There is a need in “changing laws that regulate monopolies on medicines to improve economic affordability of medicines needed by key populations and TB patients”.¹⁵

Stigma

Lack of knowledge on transmission and treatment among the general population results in stigmatizing attitudes. Stigma is stronger in rural areas and small towns.¹⁶

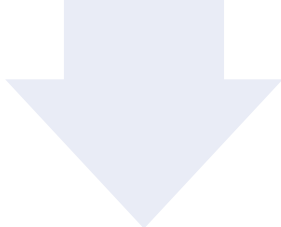
“Women and transgender people are most vulnerable to TB-related stigma”.¹⁴ Transgender people fear discrimination and violation of their rights, and this leads to delays in any medical visits. Many TB patients, mostly women, develop self-stigma.¹⁴

There is a particularly high stigma and lack of knowledge about the TB in the PHCs. There is a lack of training for medical staff on gender or training to counter TB-related stigma.¹⁴ Roma people are subject to stigmatization. The absence of identification documents, specific traditions and beliefs inside of the Roma community, results in delays of diagnosis and treatment.¹⁵ Inside the community there is a discriminatory attitude towards women and “without their husband’s consent, women cannot seek medical care”.¹⁴

There is a stigmatizing attitude by lawyers towards key populations, which discourages clients, especially from key populations, from seeking legal advice.¹⁵ People who inject drugs do not seek redress, because they do not want to attract attention of the law enforcement. This key population mentioned discriminatory attitudes of the police and the medical staff.¹⁶

Summary of CRG barriers in Ukraine

Key populations mentioned by the assessments/reviews	Specific challenges in relation to TB	Estimated size of the population
PLHIV,	Privacy, confidentiality, rights, disclosure of status	384.5 per 100 000 ¹⁵
People with alcohol dependency	No specific information	654.3 per 100 000 ¹⁵
Prisoners and detainees	Stigma	1030.9 per 100 000 ¹⁵
PWID	<ul style="list-style-type: none"> • Lack of services (OST, HIV, TB) integration • Stigma • Legal barriers • Breaches of confidentiality 	587.7 per 100 000 ¹⁵
Homeless people	Stigma	1713.9 per 100 000 ¹⁵
Urban poor	No specific information	870 per 100 000 ¹⁵
Rural poor	Remoteness and lack of funds to travel to facility	



Gender barriers

Women	Men	Other
<ul style="list-style-type: none">• Self-stigma• Psychological or financial abuse• GBV• Shame and discomfort when submitting sputum samples• Stigmatized by medical workers during examinations• Divorce/separation from children• Roma women cannot seek medical care without husband's permission	<ul style="list-style-type: none">• Fear of losing employment, while undergoing diagnosis and during treatment• High risk behaviors• Labor migration and poor working conditions• Divorce/separation from children	<ul style="list-style-type: none">• Stigma• Fear of discrimination leading to delays in seeking diagnosis and care

Human rights or legal concerns

- Right to information (lack of information about TB treatment)
- Right to work
- Right to education
- Issues around involuntary isolation and compulsory testing
- Right to privacy

Stigma/discrimination barriers

- Self-stigma
- Stigma in the workplace, including after cure and recovery
- TB/HIV co-infection, especially drug users or men who have sex with men, face double/triple stigma and discrimination, including physical violence
- Stigma from health care providers, outside of the TB program
- Stigma from the community and family members based on misconceptions
- Stronger stigma in rural areas and small towns
- Stronger stigma against Roma people with TB
- Stigmatizing attitude by lawyers towards key populations

Discussion of the main barriers and solutions

This chapter focuses on some differences or similarities in CRG barriers and solutions proposed by the CRG reports of Georgia, Kazakhstan, Kyrgyzstan, Tajikistan and Ukraine, and the extent to which these solutions were taken up in the national TB strategies. The purpose of this chapter is not to prescribe specific interventions across the region, but to underline more obscure but common barriers and solutions that may work in different settings after national and local adaptation.

Key populations:

people with a history of imprisonment and people who use drugs

People with a history of imprisonment and people who use and/or inject drugs are among the most disadvantaged populations. They are stigmatized and discriminated. People who use drugs have difficulties accessing services because of being criminalized, and people with a history of imprisonment due to the lack of a passport, domicile registration or even a home. Especially women from these key populations, experience high levels of stigma. For these key populations, any encounters with the law enforcement may result in interrupting whatever treatment they are on, which is in violation of their rights as patients and people. Possibilities of early parole for prisoners with TB (Ukraine, Georgia) may be a perverse incentive to not engage in treatment, while upon release there is usually a vacuum of assistance, including support to initiate or to continue TB treatment. The following measures were proposed in order to address some of the barriers for these and other key populations:

Improving service integration:

- Co-locating OST, HIV and TB services (Georgia, Kyrgyzstan, Ukraine) preferably in the lowest threshold setting, while maintaining privacy and confidentiality;
- Integrating TB symptoms screening and DOT in services for people with diabetes, rehabilitation services for people with alcohol dependency and for people with a history of imprisonment (Kazakhstan);
- Establishing a permanent interdisciplinary TB/HIV working group at the level of the Ministry of Health to help improve TB diagnosis in people living with HIV (Kazakhstan);
- Task-shifting to NGOs that already work with key populations and provide some of the services, such as questionnaire-based screening for TB, peer-support, legal advice, and are willing to provide a more comprehensive package of services, e.g. including OST, DOT. Task-shifting to be preceded by training and obtaining

the necessary licenses or permissions. Including these NGOs into supportive supervision, provided by the National TB Programs.

Improving service comprehensiveness:

- HIV and TB NGOs advocating for the inclusion of peer educators as members of Multi-disciplinary Teams (MDTs) and including them on the health facility payroll (Ukraine) or seconding a peer educator from an NGO to the MDT of a health facility (Kyrgyzstan), or health service contracting NGOs to provide adherence support (Kazakhstan);
- Including a legal expert in MDTs to visit prisoners with TB who prepare for release, in order to evaluate their situation and assist. If necessary, such assistance could include restoring national IDs, applying for social benefits, filing for disability, finding shelter, and most importantly, the MDT could help initiate or continue TB treatment upon release (Ukraine).

Training for police and prison staff:

- Including TB-relevant information into the HIV program's interventions on training for the police/prison staff on human rights, where such interventions already exist;
- Initiating collaboration with police administration, offering to review any human rights training materials, if such are already used by the police, to ensure up to date information about the rights to medical care for people with TB and key populations is included. Providing training for police and staff members of jails/prisons, such as professional certification and courses on tolerance (Kyrgyzstan, Ukraine);
- Introducing human rights, including right to medical care, into the curriculum of pre-service police training institutions.

Rights awareness of key populations:

- In collaboration with the National TB Program, developing a brochure with basic important information: TB symptoms, where to seek help, what services are free, and the rights of people with TB. Consequently, civil society could use it as part of their own tailored work with their clients;
- Many CSOs, primarily those of people living with HIV and people who use drugs, provide rights training and awareness sessions to their clients with good results. Similarly, organizations working with other TB-affected key populations could include TB-relevant and health rights information in conversations with their clients and constituencies.

TB in women and GBV

In all countries the proportion of notified cases is larger in men than in women. While Georgia, Kazakhstan, Kyrgyzstan and Ukraine show better adherence and/or treatment results in women than in men, women have to overcome larger barriers such as scarce finances, lack of family support and GBV. This poses a question to what extent can a smaller proportion of notifications among women be attributed to barriers encountered by women?

According to all countries' analyses, while carrying the burden of unpaid household and child caring work, women's limited decision making over household finances leads to deprioritizing their health needs and delaying TB diagnosis and sometimes treatment. It is possible that fear of TB and its consequences, which was noted in women, improves their treatment compliance. However, the motivational properties of fear are outweighed by the stress and self-stigmatization that it brings. Therefore, especially in women, the TB awareness activities need to address TB myths and misconceptions, removing self-stigma and adding positive motivators e.g. improving intra-family dynamics through family and partner counseling.

In the Kazakhstan, Kyrgyzstan and Ukraine reports, women spoke of physical, psychological and economic violence in relation to TB and violations of their reproductive rights. DR-TB in Kyrgyzstan and any form of TB in Kazakhstan are still an indication to interrupt pregnancy, although in Kazakhstan there may be plans to update the relevant guidance. Women experience violence if they have TB because of gender expectations: being/becoming mothers, being healthy in order to take care of their husbands and children/family. GBV in TB is rooted in gender stereotypes, power inequalities, lack of information and TB myths. The consequences of GBV and TB: (self-)stigma, divorce, separation from children, discontinued pregnancy, multiple issues for single mothers - are catastrophic for women. Below are some of the recommendations from the countries' reports, while some other solutions are discussed later as part of people-centered approach:

Disaggregating data:

- Disaggregating (men, women, others) all indicators, including for instance DR-TB, TB/HIV, and such TB treatment outcomes as mortality or loss to follow up, will help monitor programs and design appropriate gender-responsive interventions (Kazakhstan, Kyrgyzstan, Tajikistan, Ukraine);
- Conducting operational research could help better understand what diagnostic delays are attributable to patients and to health systems, and the role of gender.

TB and pregnancy:

- Helping pregnant women with TB understand that (1) drugs used for susceptible TB treatment regimen “do not appear to have harmful effects on the fetus”,¹⁷ (2) in DR-TB treatment, in pregnancy, injectable agents are usually contraindicated and that WHO recommends developing an individualized (longer) regimen with a lower risk to the development of an embryo or a fetus.^{18, 19}
- Providing appropriate information and counseling to pregnant women on the known and unknown risks related to DR-TB treatment.¹⁷
- Providing appropriate information and counseling to breastfeeding women, e.g. that for women taking bedaquiline, pretomanid and linezolid, breastfeeding is not recommended¹⁹ and, where necessary, facilitating alternatives to breastfeeding.¹⁹

Support to families of people with TB:

- Working with the whole family or at least with the partner of a person with TB (Kazakhstan, Kyrgyzstan, Tajikistan) will serve several important purposes: questionnaire-based screening as the first step in routine contact investigation, addressing myths and misconceptions and educating on TB, identifying potential barriers to adherence, preventing violence, ensuring family support, providing family counseling and addressing concerns. Family visits could be conducted by trained community workers or peers (former TB patients), under the conditions of strict confidentiality.

Addressing GBV

- Including a question about the situation at home in an intake questionnaire when assessing the newly diagnosed patient, if necessary, following up during subsequent meetings to understand if there is domestic violence;
- Linking GBV survivors to medical services, psychosocial support, mental health and legal services;
- Collaborating with shelters and women's organizations that focus on GBV and can help the survivors access mechanisms that may exist in-country to address GBV: i.e. support by a lawyer to file a complaint, safe space to stay while the complaint is considered and then for the time of the investigation;
- Educating shelter staff about TB and how to support GBV survivors with TB;
- Training MDTs in GBV and how to recognize and support someone who is living with an abusive partner/parent/other family member.

Stigmatization by health care workers

Stigma of key populations (all countries) and general community stigma in small towns/rural areas (in Ukraine) is often linked to a lack of confidentiality and discrimination by health care workers. Stigma from the health care staff, particularly in primary health care, was noted in the Kyrgyzstan and Kazakhstan reports. Georgia reported health staff stigma, especially directed to key populations and Ukraine and Kazakhstan pinpointed particularly stigmatizing women from key populations. DR-TB patients also experienced more stigma from health care workers (Kyrgyzstan, Tajikistan).

Stop TB Partnership's key population brief on health care workers describes in detail the increased risk of TB infection and disease among medical staff, non-responsive compensation schemes, lack of legal and labor protection and weak confidentiality. High stigma from superiors and colleagues prompts health care workers with TB to seek treatment in the private sector, self-treat, or otherwise bypass the system and not be captured in the official (occupational health and TB) statistics. On this background stigmatization of people with TB by health care workers is both paradoxical and, sadly, expected: health care workers, themselves victims of discrimination, continue to discriminate against others with TB. Addressing stigma and discrimination by health care workers needs to start with improving their working conditions, including infection control, developing and implementing strict and clear protocols regarding confidentiality, and intervening to change in-house behavior from bullying and stigmatizing to supporting and respecting.

Addressing working conditions:

- Designing interventions to improve working conditions, including (airborne) infection control at primary health care facilities. In wake of the coronavirus disease of 2019, there may be measures to improve infection prevention and control procedures initiated by governments, and the National TB Programs can use this opportunity to strengthen knowledge of PHC staff about airborne infection control and TB transmission;
- Introducing measures such as training, administrative policies, grievance procedures, to promote zero tolerance to stigma and discrimination against health care workers who fall ill with TB or any other disease, regardless of where - in the work place or in the community - they may have been infected.

Addressing stigma by health care workers:

- Organizing training for medical staff of PHC and TB services on key populations, gender, tolerance, countering stigma and upholding human rights, e.g. nondiscrimination, duty to treat, confidentiality and informed consent (Kazakhstan, Kyrgyzstan, Tajikistan, Ukraine);

- Including the topics of gender, human rights and stigma into the curriculum of pre-service, post-graduate and continuous education of medical professionals, especially for the primary care physicians (Georgia, Ukraine).

People-centered approach

The advances of ambulatory care in the EECA region are laudable, however this does not yet mean that the care becomes “people-centered” and the countries’ assessment reports once again showed that no size fits all. Even within any given key population, the conditions of people with TB vary and require a corresponding set of interventions.

Important drawbacks around switching to ambulatory care were highlighted, e.g. children in Kyrgyzstan having to be placed into sanatoria to separate them from adults with TB for the duration of the ambulatory treatment (of the adults). Across the board there is a lack of childcare provisions to be able to attend facility-based DOT which especially affects women. The difficulties of traveling to receive DOT while balancing work or education persists. Also, not all people with TB welcome visits by a DOT nurse, especially in rural areas, because of confidentiality concerns. Many respondents flagged their need for DOT outside their working hours (Georgia, Kazakhstan, Kyrgyzstan). Ambulatory care still needs more finetuning to fit the needs of patients and it can be achieved through people centered care interventions, such as outlined below.

Case management:

- Assigning a case manager to each TB patients, a case manager does not necessarily need to be a medical worker, it can be a trained staff member of an NGO. Case managers are indispensable in people-centered care, and need to have a client-oriented mindset, to help the most vulnerable navigate both public and community systems;
- Assessing each patient before treatment initiation to establish their situation, needs of financial, social and/or psychological support, possible barriers to adherence, best way of providing treatment support;
- Identifying patients to whom regular support will not be sufficient and engaging them in enhanced support;
- Enhanced support is best provided by MDTs; a designated case manager directs the enhanced support trajectory and involves different members of the MDT as required.

Confidentiality and contacts investigation:

- Case manager building rapport with the patient, explaining the importance and details of contact investigation, while safeguarding the confidentiality of a patient’s

diagnosis and motivating the patient to collaborate based on the contacts' right to health;

- Safeguarding confidentiality at all levels (NGO, MDT, health facility);
- Reporting breaches of confidentiality via community-led monitoring mechanism.

Treatment Delivery Options:

- Providing treatment delivery options, including, but not limited to clinic or hospital-based DOT, such as community DOT, Video-supported Treatment, including to key populations. Most suitable treatment delivery option and, in case of observed treatment, the choice of treatment provider, needs to be discussed at the intake with each new TB patient. This choice may be revised later on;
- Introducing testing and treatment at the place of employment;
- Evaluating different and flexible treatment delivery options and possibilities, depending on country and key population specifics, to facilitate access to such groups as daily wagers, seasonal workers, homeless persons and other key populations. There are successful examples of flexible DOT provision working in e.g. Peru.²⁰

Counseling and addressing self-stigma:

- Providing free professional psychological care for TB patients at all stages of diagnosis and treatment, including online counseling for people from rural areas/ remote districts or patients whose ability to come to the health care provider is otherwise limited;
- Conducting studies to evaluate levels of stigma and discrimination, disaggregated by gender and age, in order to analyze its impact on diagnosis and treatment, establish the baseline, indicators and monitor progress of any implementation;
- Engaging NGOs to help organize self-help groups for TB patients and their families, train and deploy peer educators and provide counseling.

The role of primary health care providers

The CRG assessments pinpoint the key role of PHC staff in TB response and, in addition to already mentioned stigma, underline PHC staff's lack of knowledge of TB and infection control and a lack of motivation, time and skills to work with clients from key populations. The following interventions could help manage the workload related to TB at PHC, ensure a more structured engagement in case management and support the continuity of TB treatment:

Involvement in TB care:

- Involving PHC staff in TB care needs to be preceded by refresher training to ensure they can recognize TB and are up to date regarding the current guidelines, diagnostic possibilities, treatment regimens, side effects, and infection control measures;
- Depending on the organization of TB care, PHC may be well positioned to be case managers, or MDT members. Such engagement requires selection and additional training.

Linking to social services:

- Promoting a dialogue between PHC and social services to improve the access of people with TB, and especially from the key populations, to social services that are available and are guaranteed by the country's legislation (Georgia, Kazakhstan).

Job security and the right to work

According to the CRG assessments findings in all countries, people with TB feel insecure about their labor rights: they either have lost work, if employed they do not know if they can continue working after returning from sick leave, often are uncertain how long their sick leave can last and if in practice it will be paid or unpaid. Legislation does not always provide the full protection of labor rights during TB treatment (Ukraine) and restrictions (Kyrgyzstan) and inconsistencies in laws or the way they are implemented in practice (Georgia, Ukraine) make it more difficult for former TB patients to find work after they are cured.

Even if laws are in place, in practice they may not work and people with TB usually do not seem to seek redress. Longer absences due to DR-TB treatment mean that at a certain point, DR-TB patients stop receiving sick leave payments and need to apply for a (temporary) disability to receive disability payments. Chances to hold employers, especially in the private sector, accountable for laying off someone with TB are small. Financial insecurity as a result of losing employment triggers treatment interruption. There are several recommendations on how to improve protection of labor rights of people with TB:

- Revising outdated legislation that limits work rights of people with TB, who are undergoing effective treatment, and cannot infect others, as was done for example in Kazakhstan;
- Adjusting legislation to guarantee preservation of work for the entire duration of TB treatment and making provisions for an accessible and uninterrupted mechanism of supporting livelihoods of people with TB while on treatment;
- Revising outdated legislation that imposes work restrictions for people who had TB in the past and have been cured;
- Making the treatment delivery system more flexible and accessible, in order for people with TB who are able to work to be able to combine work and treatment;

- Providing free legal assistance in cases of labor discrimination and labor rights violations;
- Making people with TB aware about available social support and helping them navigate the bureaucratic procedures;
- Where available and necessary, linking cured patients with rehabilitation services, whether public or provided by NGOs;
- A recommendation specific for Tajikistan, but applicable to countries with high labor migration was to “explore and implement practical options for follow-up monitoring upon departure” of former TB patients.¹¹

Active case finding in rural poor

Rural populations delay diagnoses because of remoteness of diagnostic facilities, lack of funds for transportation, lower levels of information about TB and poverty (Kazakhstan, Kyrgyzstan, Tajikistan, Ukraine). Regular DOT is often not available in rural and remote areas and patients do not receive treatment support. They often have to make out-of-pocket payments (Kyrgyzstan). Rural population is a very large group and merits a strategy of its own that will address accessibility of services, improve their quality, improve treatment support, and ensure confidentiality. Such a strategy can include:

- Dispelling myths and combating stigma from health care workers, family, employers, and the tight rural community;
- Facilitating access for women and men and preventing GBV;
- Possibly using mobile outreach clinics, while linking and integrating mobile outreach with the existing community facilities and structures;
- Improving sputum transportation (Tajikistan);
- Strengthening and utilizing existing community systems;
- Finding suitable alternatives to facility-based DOT, providing other services to strengthen adherence and reduce catastrophic costs of TB.

The role of NGOs

The need to engage different stakeholders, particularly the NGOs, and especially those that already work with key populations has been underlined in all the reports. According to the Global Fund, the interventions, particularly mobilizing and empowering groups of people affected by TB and community groups, need to go beyond service provision, and be backed up by communities systems strengthening²¹.

Needless to say, engaging NGOs and communities in formulating national TB response strategies and plans is crucial. Non-governmental and community actors need to provide their insights based on their experience of working with and representing the key populations

and ensure the programming is rights-based and gender-responsive. Subsequently to be able to follow and help implement the strategy non-governmental actors need to be trained accordingly e.g. in case management, multi-disciplinary approach, effectively addressing human rights and stigma. They need to be included in supportive supervision by the national TB programs, to ensure quality of services and two-way knowledge sharing.

The last stage of the TB journey approach, used in several CRG assessments (Georgia, Kazakhstan, Tajikistan) is follow up once a person with TB completes TB treatment. This stage should not be limited to encouraging former patients to come for a few routine monitoring checks to identify recurrence: relapses or reinfections. Post-treatment support, where NGOs could play a leading role, could help former patients reintegrate e.g. by means of assistance to find work or start self-help activities to revalidate economically, legal assistance to those who were illegally laid off or denied work because they have had TB, assistance with obtaining disability benefits for those who suffered from side effects of anti-TB treatment, legal and psychological support to women who were divorced and lost access to their children as a result of TB. For members of key populations, from the communities where behavioral and environmental risks of TB remain high, such follow up could help prevent reinfection, however such services are largely absent.

As the mandates of the civil society actors go way beyond TB service provision, they need to take a leading role in community-led monitoring and rights advocacy. This watchdog function, like service provision, needs to be backed by appropriate funding.

An important observation made by the in-depth mid-term assessment “Scaling Up Programs to Remove Human Rights-related Barriers to HIV and TB Services” conducted in 2019-2020 in Ukraine, is that a weak capacity and insufficient experience of the civil society, engaged in TB response, explains the slower progress of TB CRG interventions and “even with an increase in funds for these programs, implementing organizations will rapidly reach the limits of their capacity”.¹⁵ Some of the recommendations include:

- Ensuring an effective social contracting mechanism for NGOs to access funding;
- Capacity building of NGO’s staff to be continuous, structural and informed by their capacity building needs, and the projected needs of the program, particularly to help NGOs:
 - address human rights and stigma (Georgia, Kyrgyzstan, Ukraine);
 - take part in MDTs, as members or as case managers, including counseling skills, confidentiality protocols, symptoms screening;
 - take the lead in post-treatment follow up and rehabilitation services;

- Educating TB patients on their rights and where applicable integrating TB information to “know your rights” and “street lawyers/paralegals” interventions of the HIV programs;
- Establishing a “database of lawyers who are able, with knowledge and tolerance, to work with TB key populations”¹⁵ (Ukraine);
- Funding to NGOs in order to establish (Kazakhstan, Georgia) or, in case of Tajikistan, revive and scale up community-led monitoring. Such community-led monitoring tools already have been first piloted by Stop TB Partnership and later scaled up by PAS Center/TB-REP 2.0 project in Ukraine and rolled out under TB-REP 2.0 in Kyrgyzstan;
- Utilizing other existing mechanisms such as the National Preventive Mechanism in Ukraine to continue monitoring access to medical care in prisons and Community Advisory Boards of key population members in Kyrgyzstan to strengthen accountability, and make national decision-making more inclusive of the views of TB affected populations;
- Documenting human rights violations to support advocacy, and submit the result in the (alternative) reports of the relevant ratified international conventions.

Uptake of CRG recommendations in the national strategic plans

Only in Kyrgyzstan and Ukraine the CRG assessments preceded the development of the national strategic plans, and thus could be expected to, fully or partially, find a reflection in the national strategic priorities. In Kyrgyzstan two of the CRG assessments took place in 2016, i.e. in time to be used in the funding request to the Global Fund, which was submitted in 2017.

Example of Kyrgyzstan

Kyrgyz Republic National Program “Tuberculosis V” for 2017-2021 prioritizes work with the key populations, development of a patient-oriented treatment model and strengthening interactions within civil society. The National Program acknowledges children under 5 y.o., People living with HIV, people with chemical and alcohol dependencies, migrants, the homeless, people with a history of imprisonment, medical workers, and people with chronic diseases as key populations. It calls attention to the need of developing cross-border mechanisms for detection and treatment of TB among migrants. The National Program shows concern about the quality of TB services in PHC facilities, and the impact on treatment adherence.²²

Involvement of civil society is planned through the provision of TB services such as raising awareness, strengthening TB prevention and treatment, providing psycho-social support and reducing stigma and discrimination among key populations, including in rural areas. The National Program suggests social assistance to patients and members of their families. However, it remains silent about human rights and gender. CRG recommendations made for the penitentiary system are not reflected in the national program.

The 2018 funding requestⁱ, supported by the Global Fund, states that in response to the Global Fund’s Technical Review Panel (TRP) addressing the needs of migrants, women, children, contacts and health workers was included in the updated National Strategy. The funding request also mentions that innovative TB patient-centered approaches are provided through NGOs, however, challenges related to the integration of services remain. The funding request recognizes assessments on stigma and their findings. It also aims to improve services in the rural areas, engage NGOs in the monitoring of health services quality and promises to undertake advocacy with the government to finalize the social contracting mechanism.

ⁱ <https://data.theglobalfund.org/investments/documents/KGZ/Tuberculosis,TB|HIV> accessed on 12 June 2020.

Example of Ukraine

The National Strategy on HIV/AIDS, Tuberculosis and Viral Hepatitis Response for the period until 2030 is to a large degree based on human rights and upholds the principles of gender equality. While the document does not specify the key TB populations, it acknowledges that key populations in general are at an increased risk of TB.

The strategy prioritizes the rights to health and non-discrimination. While the Ukrainian CRG assessments focuses on cultural barriers and discrimination towards the Roma community, the National Strategy does not specify the Roma, but it does mention “removal of political, legal and cultural barriers that restrict access to services or cause stigmatization” and improving access to services of the rural populations.²³ The strategy recognizes the importance of closing the existing gaps in access to services “between urban and rural populations and individual regions” but, same as with the cultural barriers, does not go into details about the methods of addressing them.²³

The Ukrainian strategy strives to ensure that the rights of TB patients during and after treatment are respected, including “through the elimination of stigma and discrimination”. However, there is still a lack of concrete recommendations on the protection of labor and education rights during TB treatment and further, there is no mention of access to free legal advice for TB patients or “knowing your rights” education for patients.²³

CRG recommendations on the gaps in penitentiary systems do not seem to be reflected in the strategy, while many others are reflected. These include: “development of regulatory framework to monitor human rights violations”; “access to new drugs and modern shorter TB treatment regimens”; introduction of effective outpatient treatment model; provision of social and psychological support; public awareness-raising about TB; introduction of “indicators to measure gender inequality and gender sensitivity in accessing services”; ensuring active case finding among key populations; and the “development of public health human resources”.²³

Ukrainian National Strategy addresses many CRG assessment recommendations, reflects the importance of gender and human rights approach and acknowledges the gaps in TB service provision. It is likely that the upcoming implementation plan will be specific and hopefully will embark on the CRG findings and recommendations to craft measures to address key populations, human rights, stigma and gender challenges.

Conclusions

EECA is a region that sees a departure of donor organizations as individual countries' income levels rise. Common CRG findings throughout the countries included in this analysis show many inequities in accessing and remaining in TB care, as well the consequences of TB that are catastrophic to some groups of population.

CRG findings and recommendations slowly but surely find their way into countries priorities and are translated into funded interventions by informing the national strategies and being used for applications to the Global Fund. Multi-stakeholder processes that took place in all countries are certainly helpful to build the necessary consensus between people with TB, NGOs, governmental service providers, Ministries of Health, Justice and oversight structures, such as the Country Coordinating Mechanisms (CCMs). Multi-stakeholder consultations allowed the streamlining of efforts and also gave a possibility to engage some key population organizations, which previously were not very active in TB. Hopefully the recent assessments in Georgia, Kazakhstan and Tajikistan will be used by in-country stakeholders, civil society and activists, engaged in country dialogues, as evidence to guide their discussions and that the recommendations will be translated into activities and budgets.

While no one solution fits all contexts, **how** interventions are implemented does matter across settings. How to take the recommendations of this overview forward is through:

- Coordination with multi-stakeholders;
- Inclusive consultations with key populations;
- Community-led monitoring and oversight; and
- Creating enabling environments for the communities to engage in TB response.

It is of paramount importance that the upcoming National Strategic Planning exercises meaningfully engage key populations. CRG assessments that can be programmed as part of the Global Fund funding requests, will help inform strategic planning and programming. External program reviews next to the already dated Advocacy, Communication and Social Mobilization approach, must examine to what extent the countries strategies and activities are rights-based and gender-responsive and do they ensure equity i.e. leave no one behind. Country dialogues, that do not stop after the submission of the funding request to the Global Fund need to become the fora for discussing the results of community-led monitoring, engaging the key populations constituencies in governance, including through the CCMs, and pro-active collaboration between the civil society and the national TB programs.

Following the first WHO Global Ministerial Conference on TB in 2017 and the 2018 UN General Assembly resolution, WHO in collaboration with partners, developed a multisectoral accountability framework (MAF) to “accelerate progress to end tuberculosis, taking into account national context, laws, regulations and circumstances”.²⁴ The framework supports the TB related Sustainable Development Goals and the WHO’s End TB Strategy, and among other interventions, mentions the protection and promotion of human rights, ethics and equity and the engagement of civil society and the affected communities. On the EECA regional level, all stakeholders are encouraged to engage with WHO to establish the baseline and to monitor the progress of countering stigma and discrimination, eliminating human rights barriers and establishing gender-responsive TB programs.

References

1. Political declaration of the high-level meeting of the General Assembly on the fight against tuberculosis [Internet]. UN General Assembly; 2018. Available from: https://www.un.org/en/ga/search/view_doc.asp?symbol=A/RES/73/3
2. Declaration of the Rights of People Affected by Tuberculosis [Internet]. Stop TB Partnership and TB People; 2019. Available from: <http://www.stoptb.org/assets/documents/communities/Declaration%20of%20the%20rights%20of%20people%20affected%20by%20TB%20-%20A5%20english%20version.pdf>
3. Assessing Barriers to TB Services. Investment Package Community, Rights & Gender. Stop TB Partnership; 2020.
4. Mok P, Turusbekova N, Johnston L. Data for Action for Tuberculosis Key, Vulnerable and Underserved Populations. Stop TB Partnership; 2017.
5. Assessment of CRG barriers for TB high-risk groups in Georgia. Tbilisi, Georgia: New Vector; 2020.
6. The complex plan for tuberculosis control in Kazakhstan 2014-2020. 2013.
7. Оценка барьеров, касающихся правовой среды, гендера, стигмы и прав человека для ключевых групп населения в ответных мерах по туберкулезу в городе Алматы и Алматинской области. Almaty, Kazakhstan: Kazakhstan Union of PLHIV; 2020.
8. Burrows D, Bolotbaeva A, Sydykanov B. Baseline assessment - Kyrgyzstan. Scaling up Programs to Reduce Human Rights Related Barriers to HIV and TB Services. The Global Fund; 2018.
9. Sokolowski S. Tuberculosis Gender Assessment in Kyrgyzstan. Stop TB Partnership; 2016.
10. Turusbekova N. Legal Review. Tuberculosis in Kyrgyzstan. Stop TB Partnership; 2016.
11. Abdullaev T, Golichenko M, Saidova N, Stuikyte R, Shonning S, Ziyoeva S. Legal, gender, and stigma barriers to TB services in Tajikistan. 2020.
12. Mirzoev A, Lucenko I, Pirov K, Dustmatova Z, Akhmedov A, Nabirova D, et al. A Countrywide Assessment Of Tuberculosis Among Health-Care Workers In Tuberculosis Health-Care Facilities In Tajikistan, 2009–2014. Public Health Panorama. 2016 Mar;2(1):1–116.

13. Latypov A. Республика Таджикистан: Анализ устойчивости программ поддерживающей терапии агонистами опиоидов в контексте перехода от донорской поддержки к национальному финансированию. 2020.
14. Chorna Y, Kiriazova T, Makarenko O, Masiuk L, Rabinova V. Communities, rights and gender tb tools assessments in Ukraine. ICF «Alliance for Public Health»; 2017.
15. Burrows D, Kondratyuk S, Dvonkovska O. Baseline Assessment - Ukraine. Scaling up Programs to Reduce Human Rights Related Barriers to HIV and TB Services. The Global Fund; 2018.
16. Spivak N, Kondratyuk S, Demchenko K, Abdulayev T, Lukyanova N, Denysova K. Report on the legal environment assessment for TB in Ukraine. United Nations Development Programme, Stop TB Partnership; 2018.
17. TB Treatment & Pregnancy [Internet]. Centers for Disease Control and Prevention; 2016 [cited 2020 Jul 12]. Available from: <https://www.cdc.gov/tb/topic/treatment/pregnancy.htm>
18. WHO consolidated guidelines on drug-resistant tuberculosis treatment. WHO; 2019.
19. WHO Operational Handbook on Tuberculosis, Module 4: Treatment - Drug-Resistant Tuberculosis Treatment. WHO; 2020.
20. Shin S, Furin J, Bayona J, Mate K, Kim JY, Farmer P. Community-based treatment of multidrug-resistant tuberculosis in Lima, Peru: 7 years of experience. *Soc Sci Med.* 2004 Oct;59(7):1529–39.
21. Technical Brief Tuberculosis, Gender and Human Rights. The Global Fund; 2020.
22. Туберкулез-V, 2019-2021. Government of the Kyrgyz Republic; 2017.
23. The National Strategy on HIV/AIDS, Tuberculosis and Viral Hepatitis Response for the period until 2030. Cabinet of Ministers of Ukraine; 2019.
24. World Health Organization. Multisectoral accountability framework to accelerate progress to end tuberculosis by 2030 [Internet]. Geneva: World Health Organization; 2020. Available from: <https://apps.who.int/iris/handle/10665/331934>
25. WHO Quick guide to video-supported treatment of tuberculosis. World Health Organization; 2020. Available from: <https://www.euro.who.int/en/health-topics/communicable-diseases/tuberculosis/publications/2020/quick-guide-to-video-supported-treatment-of-tuberculosis-2020>

