



# COMMUNITY, RIGHTS, AND GENDER (CRG) INVESTMENT PACKAGES

TO ASSESS STIGMA, GENDER-RELATED  
AND SERVICE-RELATED BARRIERS,  
AND SET UP COMMUNITY-LED  
MONITORING

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# Acknowledgements

Brochure "Community, Rights, and Gender (CRG) investment packages to assess stigma, gender-related and service-related barriers, and set up Community-led monitoring"

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# Table of Contents

<b>Abbreviations.....</b>	<b>2</b>
<b>Introduction.....</b>	<b>3</b>
<b>1. Tuberculosis Stigma Assessment Investment Package .....</b>	<b>5</b>
Countries practice. The assessment of the magnitude of stigma in Ukraine.....	7
<b>2. Community, Rights and Gender assessment.....</b>	<b>11</b>
Countries practice. Assessment of Barriers to Tuberculosis Services in Georgia.....	14
<b>3. Community-led monitoring of the Tuberculosis response,     using the OnelImpact digital platform .....</b>	<b>16</b>
Countries practice. OnelImpact Azerbaijan .....	18
Countries practice. OnelImpact Ukraine.....	19
<b>Conclusion.....</b>	<b>21</b>



## Abbreviations

<b>AIDS</b>	Acquired immunodeficiency syndrome
<b>CBM</b>	Community-based Monitoring
<b>CLM</b>	Community-led Monitoring
<b>CRG</b>	Community, Rights, and Gender
<b>CRG SI</b>	Community Rights and Gender Strategic Initiative
<b>CSO</b>	Civil Society Organizations
<b>DOT</b>	directly observed treatment
<b>HIV</b>	Human Immunodeficiency Virus
<b>NTP</b>	National Tuberculosis Program
<b>TB</b>	Tuberculosis
<b>TGF</b>	Global Fund to fight AIDS, tuberculosis and malaria
<b>WHO</b>	World Health Organization

# INTRODUCTION

**The Communities, Rights, and Gender** (known as **CRG**) is an approach focusing on the development of community systems strengthening and aims to develop human rights based, non-stigmatizing, and gender-sensitive services for people affected not only by TB, but also by HIV/AIDS and malaria, and eliminate these above-mentioned barriers for services ('**Global Plan to End TB 2018-2022: The Paradigm Shift**').

The Global Fund has been working hard in addressing **Community, Rights, and Gender-related issues**, engaging the Civil Society and people affected by tuberculosis, and **implementing the novel funding model for the CRG**. The Global Fund also launched the **Community, Rights, and Gender Strategic Initiative** (in short CRG SI) catalytic investment program, aimed to engage the civil society and communities in Global Fund-related processes.

'**Global Plan to End TB 2018-2022: The Paradigm Shift**' drafted by the **Stop TB Partnership** presents a clear plan with estimated costs on how to achieve the targets and commitments set at the **United Nations General Assembly high-level meeting on tuberculosis** in 2018. Among the other priority actions of this document, the Stop TB Partnership is suggesting countries **use community, rights, and gender (CRG) assessment tools (called CRG Investment packages)**, to assess which populations are the most vulnerable and based on the assessment define policies that aim to eliminate barriers that prevent access to TB treatment and care.

The main aim of this brochure is to inform the National Tuberculosis Programs, Civil Society Organizations, Tuberculosis (TB) affected community, and stakeholders about the three assessment tools developed recently by the STOP TB Partnership.

We are pleased to **introduce these tools**, discuss their **benefits for the National Tuberculosis Programs, civil society and TB affected community** and give a short overview of **how to plan, design, and implement these instruments at the national or sub-national level, and to use to improve during applying for funding**.

All these working documents aimed to explore **stigma (Assessing TB Stigma and TB Stigma Assessment Implementation Handbook)**, gender-related barriers (**Gender and TB**) and set up the **Community-based Monitoring (CBM) (Community-based monitoring of the TB response, using the OnelImpact digital platform)** can be found from the **Stop TB Partnership website**.

All the assessment **CRG tools/investment packages** developed by the Stop TB Partnership, are comprehensive guides that assist in conducting an assessment based on quantitative and **qualitative research methodology to explore various CRG barriers**.

- **OnelImpact** is a digital health solution to support community-led monitoring of the TB response developed by the Stop TB Partnership and launched by Dure Technologies.  
Setting up a digital monitoring system is the best way to improve the availability, acceptability, quality, and equity of TB services and make the quality services accessible for anyone who needs it.
- So far in EECA region seven countries, **Azerbaijan, Belarus, Georgia, Kazakhstan, Kyrgyzstan, Tajikistan and Ukraine**, are using OnelImpact smartphone app for Community-led Monitoring of TB treatment.

Georgia ([Union “New Vector”, 2020](#)), Ukraine ([Alliance for Public Health, 2018; UNDP& Stop TB Partnership. 2018](#)), Kazakhstan ([Kazakhstan Union of People Living with HIV, 2020](#)), Kyrgyzstan ([Sokolowska, 2016; Turusbekova, 2016](#)) as well as Armenia, Moldova and Tajikistan have conducted CRG assessments.

Data gathered through the Community-based Monitoring (CBM) (known as **OnelImpact** app) and CRG assessments give **evidence-based data vital to plan and improve TB response, strategic national action plans, and develop services that fit best for people affected by tuberculosis and into the local context and apply for funding from the Global Fund to Fight AIDS, Tuberculosis, and Malaria.**

The expected outcome of the assessment tools are **human rights-based, people-centered, gender-sensitive, and non-stigmatizing** services that **best meet the needs of people with tuberculosis in the community.**

- Within this brochure, we will also introduce a stigma assessment tool and handbook for helping countries and civil society, and communities investigating and addressing TB stigma.

Among others, these assessment tools are useful to **move finally towards non-stigmatizing language and dignified prevention, treatment, and care** TB survivors, Civil Society Organizations, and researchers have advocated and fought fearlessly for many decades ([Frick, Von Delane, Blessina, 2015](#)).

All **Community Rights and Gender** (CRG) assessment tools (called CRG Investment Packages) are available at the [Stop TB Partnership website section on Communities, Human Rights and Gender](#).

Together with the [Stop TB Partnership TB Europe Coalition](#) (TBEC) encourages countries to include Community, Rights, and Gender priorities in the funding request to the Global Fund to Fight AIDS, Tuberculosis, and Malaria for grants. All information on how to draft the funding request for the Global Fund is available in the [Applicant Handbook 2020-2022](#) published by the Global Fund.

# 1. TUBERCULOSIS STIGMA ASSESSMENT INVESTMENT PACKAGE

Stigma is the common barrier preventing people affected by TB from getting screened, tested, diagnosed, starting timely treatment, and completing treatment ([Gentnet et al, 2017](#)). Literature review shows that stigma is related to poor health outcomes and delayed healthcare and treatment-seeking, poor recovery, affects negatively family's reputation that could harmfully effect the possibility of getting a job, education, and getting married ([Kane et al, 2019](#)).

Stigma is causing the loss of support, mistreatment, and reduced treatment quality and wellbeing, and limited knowledge of TB in society and community which leads to stigmatization and discrimination ([Sagili et al, 2016](#)).

There are some evidence-based interventions proven to be effective in reducing stigma related to tuberculosis. Research has shown very clearly that interventions aimed to improve knowledge and attitudes of general population, patients and their families and support patients via supportive and encouraging home visits and support groups are effective in reducing tuberculosis related stigma ([Sommerland et al, 2017](#)).

The **TB Stigma Assessment Investment Package** developed by the STOP TB Partnership is guiding countries, communities, and civil societies to investigate TB stigma and use its results to eliminate it via more effective, people-centered, and gender-responsive policies, strategies, and specific actions. The Stigma Assessment Investment Package is available at the [STOP TB Partnership website](#).

This **Community, Rights, and Gender (CRG) stigma assessment tool** helps to evaluate the level and dimension of different types of stigma related to tuberculosis using quantitative and qualitative study methods.

Study results help to create **evidence-based and non-stigmatizing policies** and design and implement **actions and interventions that fully respect the rights of people with tuberculosis**. The working document gives an overview on how to conduct a study aimed to assess stigma involving people diagnosed with tuberculosis and their family members, the community, health care medical personnel, and various other stakeholders, including civil society, and policy and decision-makers. A planned assessment study takes from 6 to 12 months and consists of **desk review, individual interviews** using interviewer-administered and validated semi-structured questionnaire and **focus group interviews** with various stakeholders having the best possible knowledge on local tuberculosis situation and responses. Stigma assessments were carried out in the two countries of the EECA region, Moldova and Ukraine.

The first step of TB Stigma assessment is to hire a **stigma expert** and form a **Technical Working Group**. A stigma expert will conduct **desk-review**, draft the initial **stigma assessment study protocol**. It should be discussed and agreed upon with the Technical Working Group and sent to the **Ethical Committee for ethical approval**. Sometimes it takes a lot of time to reach a consensus about the Stigma Assessment Protocol. Meanwhile, a TB Stigma expert and Community-led organizations can provide **training of study staff**. They should contact sites where the assessment will take place. A study team can start to recruit study participants for **Focus Group Discussion** and individual interviews. TB Stigma expert (ideally statistician, but not necessarily) can then **analyze data, write a report**, and draft



**initial recommendations.** However, the assessment report should be presented and discussed by the organization responsible for assessment, stigma expert, and all the members of the core working group.

Study's initial and final findings, suggestions and conclusions should be discussed along with every member of the working group, donors, CSOs and people affected by tuberculosis. It helps to validate findings, recommendations and conclusions.

It is very important to define very **clear recommendations** and **draft the final report**. At this stage of a study, it is time to draft a **communication strategy** with clear messages for different audience and write a detailed dissemination plan of assessment results. Meanwhile, the stigma expert with the costing consultant can start drafting the **TB Stigma operational plan**, which will be **discussed with multi-stakeholders** and sent to the Core Working Group for their input.

The final findings of stigma assessment allow drafting Stigma Reduction Operational Plan that also consists of estimated cost. It also helps to put together strategic guidance from the National Tuberculosis Program.

According to the methodology of the Stop TB Partnership, this plan will be discussed by a **multi-sectoral working group**, including also CSOs and people affected by TB, and it should be **approved by the National Tuberculosis Program (NTP)**. In the **stigma assessment tool**, the whole process is described in detail and consists of an excellent example of how to **plan resources for the stigma assessment**.

## TB Stigma Assessment Implementation Handbook

The Stop TB Partnership has published the **TB Stigma Assessment Implementation Handbook**. This handbook describes in-depth steps by steps on how to conduct stigma assessment (goals, target audiences, human resources needed, methodology, individual and focus group interviews, timeline, budget, ethical approval for a study protocol, data collection, data entry, and analysis, findings, and recommendations, discussion of research findings, budgeted action plan, planning and implementation of communication and dissemination), and gives an overview of types of stigma. This document is available on the **Stop TB Partnership website**. Besides, this voluminous handbook contains examples of various documents needed to conduct a stigma assessment study. In the beginning, the **TB Stigma Assessment Implementation Handbook** gives a reader a clear definition of different types of stigma. This is a good starting point for planning a stigma assessment and it helps to define if to investigate all types of stigma or focus on the investigation of a certain type of stigma. As the handbook states – **to end stigma is equal to the end of tuberculosis**.



# TB Stigma Assessment Data Collection Instrument. Key Informant semi-structured interviews § Focus Group Discussion Guides

The Stop TB Partnership has also developed a very useful document entitled “**TB Stigma Assessment Data Collection Instrument. Key Informant semi-structured interviews & Focus Group Discussion Guides**”. Among other useful materials, this document contains a sample of **informed consent forms** and **questionnaires** for semi-structured interviews with different target groups for stigma research project. This document presents **examples of study instruments**, which are easy to **adapt to the local context**. This well-written document on TB Stigma assessment instruments consists of the Law and Policy Scoring Matrices for focus group discussions for key-informants. This handbook is a perfect reading for anyone planning to assess the stigma and discrimination associated with tuberculosis in their country. It makes the planning and preparation of the study easier.

## Countries practice. The assessment of the magnitude of stigma in Ukraine

Ukraine started to assess the magnitude and nature of stigmatization among people affected by TB and currently on TB treatment in 2020 using **the Stop TB Stigma Assessment tool**. Among the others, the research team is investigating **self-stigmatization** and **secondary stigma derived from relatives and family members**. The study aims to assess the magnitude of **stigmatization in the local communities and healthcare facilities** offering TB treatment. They also explore the less studied area – **stigma towards medical staff working at the TB clinics from other medical professionals**. Stigma assessment started in Ukraine in the summer of 2020 in 14 regions out of 27. The aim is to recruit 1100 people currently on tuberculosis treatment and 240 medical staff. Also, 38 community members and 44 family members of people with TB were interviewed.

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*“Speaking about stigma, it is not only Ukraine but the whole EECA region needs to investigate and reduce (stigma). Including the stigma that can be caused by medical professionals. Many studies confirm that stigmatization by the society and health professionals affects the success of tuberculosis treatment. Medical professionals themselves often do not feel how stigma affects the treatment process. If there is a stigma in society, people ill with tuberculosis or with symptoms of TB will not receive timely medical care or it will be provided to them when they are in a very critical condition.”*

**Vladyslav Denysenko,**  
*Senior Officer at 100% Life (former the Network of PLWH)*

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Read more about this study in Ukraine from the TB Europe Coalition website (**Stigma - an underestimated barrier on the way to care for people affected by TB**) and you can find final report «TB STIGMA ASSESSMENT IN UKRAINE» on the [100% Life website](#).

# Practical steps to conduct a stigma assessment

- ▶ **Careful preparation, a well-trained research team, involvement of all key persons, being ready to adapt, and effective communication are key to the successful assessment of tuberculosis stigmas.**

If you want to assess stigma, you need the **right methodology, research tools**, an **excellent expert research team, working group, good communication** with TB patients, clinics, and the community and coordination.

**Even if the study is well prepared, obstacles may arise**, which might require significant changes in the recruitment process or timeframe. For example, **due to the COVID-19 pandemic, face-to-face interviews need to be replaced by telephone interviews**. However, this will take much longer. Also, the planned **stigma assessment may be affected by the reform of TB services**. Recruitment may also be affected by other factors, such as the **negative attitude of a treatment center or community towards the study**. It requires a **flexible approach**, and the **ability to work together effectively** from the study team and those responsible for recruiting study participants in TB treatment centers. It is also vital to **communicate with other partners of the assessment**, including the funder, to inform them of the factors that hinder the study process and **work together to find a solution**.

- ▶ **Assessment ethics and the involvement of representatives of the TB community in the study are crucial.**

When assessing stigma, it is vital **to involve the TB community in the study**. They need **training** to interview study participants and conduct focus groups if necessary. It is also important to **find suitable working hours to avoid a loss of motivation** for both the study team and the TB community involved. Participation in stigma assessment, as in any study, is **voluntary**. As part of the **informed consent process**, the **participant should get information** on the **assessment objective**, the **methodology**, the **benefits** of participating in the study, including the **benefits and potential harms** of participating.

- ▶ **Choose the right strategy for recruitment of study participants, involve TB treatment centers and be flexible to find new solutions.**

Recruiting study participants to assess the stigma is often a challenge for a research team. Even more so as stigma assessments might be carried out in **different regions** and often based on **TB treatment centers with very different work cultures**. A stigma assessment study needs to **combine various strategies for recruiting study participants** or **find better-suited innovative solutions**.

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*"In the process of conducting the survey in some districts we were surprised that people strongly refused to participate. Many said they did not want to talk about treatment. There was something in the dispensary that affected the patients so that they did not want to speak."*

**Vladyslav Denysenko,**  
Senior Officer at 100% Life (former the Network of PLWH)

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When assessing stigma, **unexpected situations may arise that limit the recruitment of potential participants** including the COVID-19 pandemic. A good research team can overcome all difficulties. Various interventions are beneficial to recruit participants for an evaluation study. For example, **clear information for potential study participants, promotion** (advertising, press releases, presentations, events), **convenient location, training for a research team and recruitment staff, motivating incentives** (gifts for staff, co-authorship for site recruiters, monetary incentives), good **design of an assessment**, the **involvement of people affected by TB and patients or their organizations**, recruiters and the community, **piloting of study instruments**, more **effective communication** (face-to-face visits to the recruitment center and **regular and ongoing communication** with recruiters at the treatment center) and **better financial resources** (Bower et al, 2014).

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*"Many TB treatment centers began to provide care to COVID patients as well. We found that medical staff (in TB treatment centers) did not have time to deal with TB patients in our study. They provided treatment to patients with coronavirus and did not have time for a study. Therefore, in some districts, we replaced the coordinators with those who had more free time. That is how we resolved this situation."*

**Vladyslav Denysenko,**  
Senior Officer at 100% Life (former the Network of PLWH)

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## ► Challenges of a multilingual environment

It is crucial to ensure that the **language used is understandable by the target group**. Moreover, it is of utmost importance to pilot the **adapted questionnaire among the target group**. If the study is planned to be conducted in a multilingual country or region, it might be necessary to use **multilingual research tools**. It also requires hiring interviewers who speak these languages.

## ► Cooperation and support from key institutions are essential in carrying out the evaluation.

The **support of the study team from various stakeholders is necessary** for the smooth running of the study. The Stop TB Stigma Assessment Guide also recommends setting up a **working group to coordinate the assessment** study and **validate the recommendations and action plan**. Why is there a need for evaluation support and assistance from national structures?

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*"We had the process organized in a way that the data on patients was given to us by the Public Health Center. The sampling must be random, and the code can only be obtained from the Public Health Center. Alternatively, the interviewer goes to the TB dispensary and interviews patients there. Support is needed from the TB dispensary where the interviewer will work. The state support is always needed. It simplifies the work. It is sensible to involve also other institutions and organizations in the evaluation as these can help solve various problems that hinder the course of the study. So, through partner organizations, for example, we contacted family doctors."*

**Vladyslav Denysenko,**  
Senior Officer at 100% Life  
(former the Network of PLWH)

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## ► Why to assess stigma and how to use results?

Based on the results of the CRG assessment countries can develop nationwide human rights-based, gender-sensitive, and people-centered evidence-based and non-stigmatizing tuberculosis policies, treatment, care, and other services and interventions.

The results of the stigma assessment study make it possible to integrate interventions reducing stigma and discrimination at the heart of the national strategy and action plan to fight tuberculosis. Stigma assessment and Action Plan based on it put people exposed to TB in first place and help to eliminate barriers preventing them from getting all services they need for treatment and recovery (**The results of the stigma assess A Deadly Divide: TB Commitments vs. TB Realities**).

The interventions planned as a result of the evaluation will **help to reduce stigma and discrimination** among people affected by TB. The results of the evaluation will also help to raise funds from the Global Fund to reduce stigma and for new research.

## 2. COMMUNITY, RIGHTS AND GENDER ASSESSMENT

It is known that **gender-related barriers limit the access to TB diagnostic and treatment and its outcome**. For example, a recent review ([Laksim et al, 2014](#)) showed that women face more **household-related stigma** (low status and lack of independence), **low health literacy, financial** (lack of autonomy), and **psychosocial isolation barriers**. On the contrary, men experienced **community-led stigma** and **work-related financial and physical barriers to care**. Both genders experienced physical (such as long travel time, inflexible open hours, long waiting time etc.), and care provider barriers (poorly equipped hospitals, delay in diagnosis, loss of privacy and confidentiality etc.).

These **barriers affect the accessibility, affordability, and outcome of TB care**. It also shows how important to explore **context-specific gender barriers** to develop **gender-specific effective TB treatment and care** in the community and treatment facilities. Policies and strategic plans should ensure **gender equity** and invest in **male-and female-friendly prevention, screening, diagnostics, treatment, and care**.

Epidemiological studies conducted in low-and middle-income countries have shown that **TB prevalence is higher among men than women**, and it turned out that **men are also more likely diagnosed very late** and die due to TB ([Horton et al, 2016](#)). Evidence shows that differences in gender disparities in social interaction is causing a **higher TB burden among men**. It demonstrates clearly that there is a need also to invest in **male-friendly TB services globally**.

It is well-known that **TB-related deaths could be prevented by better and timely screening, diagnosing, and treating TB disease**. A recent (2019) meta-analysis showed that along with other factors such as non-smoking, nondrinking, being HIV negative, being younger than 65, and being female is related to TB treatment success ([Chaves et al, 2019](#)).

The Stop TB Partnership has developed a handbook "**Gender assessment tool for national**" that allows countries to **conduct qualitative studies aimed to evaluate how gender disparities are related to TB treatment and care in a different context**. This guideline is a good starting point for anyone who wishes to conduct a study exploring **gender barriers**. It shows **what kind of information is useful to collect** on epidemics and national TB/HIV response. It navigates you smoothly throughout the **data analysis**. Besides, it gives hints about **how to use assessment results and recommendation to improve gender-transformative interventions**.

Moreover, there is a **glossary** at the end of the guideline helping anyone with **terminology**. The **Gender Assessment Tool for National HIV and TB responses** developed by the Stop TB Partnership and UNAIDS can be downloaded at the [Stop TB Partnership website](#).

The Gender Assessment Tool for National HIV and TB responses gives knowledge of how to do TB gender assessment and gives an excellent overview of terminology (e.g., **gender equality, gender identity, gender-related barriers** etc.). **The Gender and TB Investment Package. Community, Rights, and Gender** developed by the Stop TB Partnership demonstrates and gives guidance on how TB programs can put gender center of planning and implementation of their national program activities.

This tool helps countries to **assess their HIV, TB, or HIV and TB co-infection epidemic** and **taken measures from a gender perspective** and **identify gender-related barriers** to treatment and care and **create a gender-sensitive response**. It is available on the **STOP TB Partnership website**.

The results of the assessment give the countries valuable information on how to create gender-sensitive/responsive policies and design accessible, people-centered, gender-responsive, and supportive community-led and/or health-care services respecting the rights of people with TB and meet their needs and supports their full recovery.

The Stop TB Partnership helped conduct the Community Rights and Gender (CRG) Assessments in more than ten countries so far, and the findings were quite similar in every country. For example, **the lack of gender equity and widely prevalent gender bias** among healthcare staff, **limited gender-specific data**, the **absence of gender-specific monitoring and evaluation**, and **gender-blind TB policy**, the widespread **TB-related stigma** limiting access to TB services in most countries studied.

The **Gender and Tuberculosis investment package** guides how countries can **improve their TB response** and become more **gender-responsive** through the usage of their assessment results and **setting up gender-specific monitoring and evaluation** to improve services.

The desired outcome of this assessment is the implementation of gender-responsive policies, national TB strategies and action plans, gender equity in the TB workforce, and interventions designed to fit best care and treatment needs of all genders.

In other words, it helps to improve the quality of **gender-responsive facility-based services** (gender-friendly environment, suitable opening hours, integrated TB and HIV services, screening, diagnostic and treatment algorithms, gender-specific psychosocial and other support, door-to-door case finding, gender-responsive community-case finding, counseling). Moreover, **a gender-specific stigma assessment is beneficial to reduce stigma, discrimination, and isolation of people affected by tuberculosis**. This assessment tool is dealing briefly with **gender-responsive TB services for people who use drugs**.

Identifying eliminating patient- and system-level CRG barriers to TB services is critical in every country tackling with tuberculosis epidemic.

It is well known that removing barriers to TB treatment and care improves treatment outcomes substantially.

A systematic review of the literature (**Sullivan, Esmaili, Cunningham, 2017**) has shown that poor health-seeking behavior (limited knowledge, unfavorable attitude, and false beliefs related to tuberculosis), stigma, and poorly integrated services (too centralized services, a long-distance, delay and poor quality of services, long waiting times, and hierarchical healthcare services) limit the initiation of treatment.

For example, the **assessment aimed to investigate barriers to TB treatment in Ukraine** found that loss of income, the high cost of additional medications, long-distance and costly traveling to the hospital, delayed healthcare seeking due to limited income, belief that medical personnel are incompetent and cannot help, underfinanced healthcare facilities, and mental health problems due to isolation and unfavorable attitude towards patients and



very strictly implemented hospital-based directly observed treatment (DOT), and poor management of side-effects limited the treatment adherence ([Aibana et al, 2020](#)).

Knowing these problems, we can improve the situation by integrating respective measures into national TB policy and activities.

The Stop TB Partnership's publication on [Assessing Barriers to Tuberculosis Services](#) gives an overview about the **objective and scope of the assessment**, describes in-depth areas of **intervention, processes, expected results, resources** need and on how to apply for funding from the Global Fund. This document is available on the [Stop TB Partnership website](#).

The working document aims to give the reader an overview **of how to assess barriers to tuberculosis services**. This assessment consists of the **revision of the current TB policy and legal framework, investigation of existing data** to find out existing and missing data about vulnerable groups affected by TB. This assessment explores **how stigma related to tuberculosis and gender-specific barriers affects access to different TB services and treatment and care as well as its outcomes**. The working document of the Stop TB Partnership gives good tips on how to develop a **budgeted national action plan based on assessment findings and recommendations** and define a setup for the implementation of the agreed plan.

The methodology and processes of the assessment are like the stigma and gender assessment. Similarly, with stigma assessment, for this assessment, there is a need to ensure the state-level contribution and support. It is very important to **establish a core working group** with various stakeholders (including SCOs and people affected by tuberculosis), and **very clearly define roles, goals, scope, and timeframe of the assessment**. The assessment of barriers to TB services consists of a combination of qualitative and quantitative research methodology. The Stop TB partnership guidance suggests undertaking a desk review to get an overview of existing data and previous research. It also helps to define the goals of an assessment and vulnerable groups affected by TB the most.

Before the implementation of an assessment, it is of utmost importance **to discuss and agree with various stakeholders all issues related to planned assessment study**, write a **study protocol**, and work out **tools** (questionnaires, informed consent, interviewing plan for Focus Groups etc.), and **obtain Ethical Approval from the Ethical Committee**.

Data collection includes **desk review** we spoke about earlier, and **individual interviewer-administered interviews, in-depth individual, and focus group interviews**.

**After data is analyzed and a preliminary overview of study results, findings, and recommendations completed, stakeholders should discuss it** during a well-organized meeting. It ensures that the **final report contains diverse recommendations allowing to draft national TB action plan with a clear budget** and an accountability framework for this plan.

The Stop TB Partnership's assessment result leads to **improved knowledge about legal, gender-specific, stigma, and services-related barriers** that limit the possibility of people affected by TB to get easily accessible, high-quality, gender-sensitive and people-centered treatment.

As a result, it **helps to change current unfavorable national laws, policies, and strategies** in the country and **strengthen cooperation between various stakeholders**.

The one clear benefit is that stakeholders engaged with the assessment process **achieve consensus about targeted actions aimed to improve TB response**.



Conducted assessment and national action plan based on the assessment results are helpful to apply for funding from the Global Fund and other international organizations.

For example, throughout the **Breaking Down Barriers initiative**, the Global Fund allocated additional funds to scale up evidence-based programming to eliminate human rights-related barriers to three diseases (HIV, TB, and malaria) services (see **Step Up the Fight. Focus on Human Rights**). From the EECA region, Kyrgyzstan and Ukraine are among 20 countries to participate in the Global Fund 'Breaking Down Barriers Initiative'.

As stated by the **Global Fund Strategy for the years 2017-2022** human rights and gender equity is one key objective.

From the Global Fund website, you can read their latest reports, guides, and other documents on **Community, Rights, and Gender**, including 'Breaking Down Barriers Initiative' under Human rights subsection.

## Countries practice. Assessment of Barriers to Tuberculosis Services in Georgia

The CRG assessment in Georgia was conducted in 2020 using the **TB Community, Rights, and Gender tools** developed by the **Stop TB Partnership**. The final study report "Assessment of CRG barriers for TB high-risk groups in Georgia" is available at the **Stop TB Partnership website** and **PAS Centre website**. We recommend reading this very well-written report as it comprises examples of all study instruments (interview guides, Informed Consent form, etc.) used for a research project in Georgia.

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*"We used several CRG tools and carried out practical activities. First, our organization, 'New Vector' focused on conducting a desk-review (cabinet survey). We looked at the legal context of tuberculosis in Georgia, the country's research on the subject. Besides, we looked at the context of TB risk groups. We presented these results to all interested parties, including national and non-governmental organizations and decision-makers in national-level structures."*


**Konstantine Labartkava,**  
Director of the Union  
"New Vector"

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The best starting point of the assessment study is the appropriate methodology and involvement of multi-stakeholders. It helps define the assessment goals, target group, and right methods and validate the results. In Georgia, one multi-stakeholders working group meeting took place at the beginning of a study to set the assessment priorities. The second meeting aimed to discuss the results and develop an action plan on how to overcome barriers. A permanent working group has been formed in Georgia to guide and monitor the implementation of the CRG assessment.

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*"We conducted a qualitative survey, including personal interviews with key people, including in-depth interviews with NGOs, people with TB and their families, and service providers. We conducted several focus groups, in which 6-10 people participated in each of them. We conducted 25 interviews with key individuals. The focus groups included people who had recovered from or were on tuberculosis treatment. There*



*were also more general focus groups and those involving medical staff. In total, we conducted 56 interviews and ten focus groups. After this another working group was held to discuss the route of TB symptomatic treatment with the aim to seek help from a treatment center, getting a correct diagnosis, starting treatment and support during treatment, including receiving follow-up support services. Based on all this, we developed recommendations and actions."*

**Konstantine Labarkava,**  
*Director of the Union "New Vector"*

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As a result of the survey, Georgia established strengthened cooperation between state and non-profit organizations. Non-profit organizations, including New Vector, TB People, etc. signed a memorandum with the Tuberculosis Centre. In addition to the information campaign, video material for general population about the stages of the TB journey was produced and additionally brochures were developed. The training was provided to non-profit associations and to groups at high risk of tuberculosis.

The one clear benefit of the CRG assessment is the engaging of stakeholders with the assessment process to achieve consensus about targeted actions aimed to improve TB response. Read More about the assessment on the community, rights, gender, and stigma in Georgia from the [TB Europe Coalition website](#).

### 3. COMMUNITY-LED MONITORING OF THE TUBERCULOSIS RESPONSE, USING THE ONEIMPACT DIGITAL PLATFORM

The Stop TB Partnership developed a digital solution called **OneImpact**, which allows collecting **real-time data** on the **implementation of Community-led monitoring (CLM)** interventions. The smartphone-based digital solution aims to **improve TB treatment** by systematically **collecting data on different barriers (economic, social, human rights, stigma)**, which prevent people with TB from getting treatment and help to resolve these problems in case they report it. This smartphone app allows **people with tuberculosis** to **connect easily** with people having the same disease, **treatment centers, patient organizations, and support groups, access to TB services** and **vital and useful information** that he/she might need, and most importantly **report various problems people TB treatment face**.

The **OneImpact app** includes the following five modules:

- **Get to Know Your Rights** - Get information on the rights of people affected by TB and the state's responsibilities to ensure those rights.
- **Get Knowledgeable** - allows you to easily get information on TB from medical doctors, from people affected by TB, Stop TB Partnership, and TB Community Networks.
- **Get Access** - helps to find health and support services for people affected by TB (peer support groups, psychosocial support, etc.), and connects with the National TB program, and National TB Partnership.
- **Get Connected** - an opportunity to connect and interact with other peers affected by TB and peer support groups, interact in discussion forums on TB.
- **Get Involved** - allows you to register various TB services, human rights barriers, stigmatization, and discrimination related to TB and get an overview of the status of the complaint and receive feedback.

This app gives user **evidence-based information on TB, TB services, allows interaction with other people with TB, TB support groups, and TB survivors, and reports service-related barriers**. It means that people affected by TB who are using this digital solution are **better informed about TB and their rights**. Moreover, people affected by TB are encouraged to **report confidentially about any barrier related to services**. Thus, they are **involved in designing patient-friendly treatment** fully supporting their cure from TB.

The First responder dashboard is designed to monitor service barriers and respond to problems reported by people affected by TB. The Accountability dashboard gives data useful to design and improve interventions or services for people affected by TB. Also, collected information on different community-led indicators gives the possibility to write better grant applications.

The community-led monitoring is a fast way to **improve availability, acceptability, and quality of TB services** using **gathered data, improve the quality of services** and make

them easily accessible for any person who needs TB treatment. Community-led organizations can implement OnelImpact to monitor the human rights barriers (availability, accessibility, acceptability, quality, and equity) of services and overcome these barriers by analyzing collected data for decision-making.

The community-led monitoring **involves the community, including civil society**, and based on locally gathered real-time data via OnelImpact app.

We can conclude that ongoing monitoring helps countries to inform and reform policies and improve decision-making on tuberculosis response in the country. The monitoring app can be easily adapted and downloaded from **Google Play**.

Analyzing data collected via OnelImpact app gives countries and more specifically the **National Tuberculosis Programs (NTPs)** a great opportunity for **evidence-based policy and decision-making** in the field of TB. OnelImpact allows the service provider to **create interactive** and **easy-to-download reports**. However, this tool can be used to identify **various barriers to tuberculosis services** if they are **reported by users - people affected by TB**.

For example, **finding problems related to availability, accessibility, acceptability, and quality of tuberculosis treatment** or its support services allows the National TB Program the possibility to **address and eliminate these barriers** without delay. It helps to **reduce the vulnerability of people with tuberculosis, improves access and quality of services**, and as a result, it increases the treatment success.

One clear benefit of OnelImpact developed by Stop TB Partnership is a more focused work all implementing countries are doing to **empower TB Affected Communities to Transform the TB Response to be Equitable, Rights-Based & People-Centered**. Along with the Stop TB Partnership support, for all barriers, identified **countries drafted their response protocols**. These protocols foreseen actions implemented by the **multi-sectoral response teams to overcome barrier and provide a better link to people affected by TB to the community, health, social welfare**. Moreover, data gathered via the OnelImpact allows countries to **set their clear advocacy priorities**.

It is possible to **add new features to the OnelImpact app** in collaboration with the app management and development agency. For example, by **adding COVID-19 chapter**, it is possible for people in TB treatment using OnelImpact to report problems through the app that negatively affect their treatment outcome due to the **coronavirus pandemic**. Besides, the OnelImpact helps people with TB and their families improving their knowledge of this disease, makes treatment and care of TB and DR-TB more convenient and patient-friendly, and if necessary, links patients with other services to achieve the desired treatment outcome.

In the Eastern Europe and Central-Asia seven countries, **Azerbaijan, Belarus, Georgia, Kazakhstan, Kyrgyzstan, Tajikistan, and Ukraine**, have **implemented the electronic community-led monitoring system OnelImpact** to help people to **access more easily to treatment, improve treatment outcome** and report **and solve complaints related to services**.

The guidance of **Community-led monitoring OnelImpact** is available at the website the **Stop TB Partnership**. We also recommend that you check out the resources from the Stop TB website OnelImpact section, which contains rich information about the OnelImpact mobile app. It is possible to get information on the conceptual framework, feasibility and

assessment, tools adaptation, training materials, launch, monitoring and evaluation, and Case Studies.

This e-health app is an **extraordinarily great tool for people affected by TB** and compliant with data protection rules. **It does not allow to identify a person.** It helps people affected by TB to **complete treatment successfully** and **report problems that negatively affect their recovery.** Besides, it is **beneficial for the country**, as data on TB monitoring and evaluation collected via the OnelImpact app allows to **plan and design well-functioning and high-quality TB services.**

The OnelImpact innovative e-health solution has been developed to focus on human rights as well. It might be **implemented by the National TB Program** or committed **Civil Society Organizations.**

The implementation of OnelImpact digital solutions relies on the meaningful engagement of all key-stakeholders – the affected TB community, people diagnosed with TB, community-led organizations, peer support groups, community health workers, health care providers, and decision-makers.

To set up the Community-led monitoring takes 6 phases (feasibility and needs assessment, the adaption of a digital platform, development of the digital solution, user training, launch, ongoing real-time data collection and community responses, evaluation, and scale-up) and 19 steps. **The Stop TB Partnership investment package** describes well the whole process for anyone interested in the implementation of OnelImpact.

Also, the Global Fund urges all countries to scale up community-led monitoring system to improve the quality of grant applications and efficiency of investments into TB services and link it with national monitoring systems.

Moreover, the usage of CBM data **substantially improves decision-making and allocation of funding** at the country and regional level. Countries that have not implemented **OnelImpact can consider applying for a grant to establish it.** Countries can rely on technical assistance from the Stop TB Partnership if they wish to implement OnelImpact in their country.

There are seven countries in EECA region (**Azerbaijan, Belarus, Georgia, Kazakhstan, Kyrgyzstan, Tajikistan, and Ukraine**) that have implemented the OnelImpact app. The Stop TB Partnership continues to develop and improve the usage, usefulness, functionality, and technical support of the OnelImpact app. The monitoring app can be easily adapted and used within a year, and the Stop TB Partnership encourages countries to use it.

## Countries practice. OnelImpact Azerbaijan

The Global Fund to Fight AIDS, Tuberculosis, and Malaria supported the development of the **OnelImpact Azerbaijan** smartphone app developed and adapted by “Saglamliga Khidmat” Public Union on the framework of the TB-REP-2.0 program.

The **app** was developed and launched at the national level within a relatively short period (from June 2019 to June 2020). It was advertised widely on national TV. Data collected using this app showed that it **helped to detect gender-related stigma** and other barriers people with TB were still facing.

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*"The introduction of this tool has further strengthened partnerships between stakeholders in the Republic of Azerbaijan aimed at helping and supporting people affected by TB. Onelmpact enabled us to identify the main barriers that people with TB face. More than half of the requests are related to economic barriers, the second place is taken by the problems of stigmatization of people with TB, a third of requests are related to the need for social services, the issues regarding treatment are also received. In addition to directly supporting people affected by TB and responding to their problems, we use this data to create a convincing evidence base for further advocacy activities."*

**Parvana Valiyeva,**  
Executive Director of the Saglamliga  
Khidmat Public Union, Azerbaijan

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According to the data of the Onelmpact Azerbaijan, at the beginning of February 2022, altogether 1385 people affected by TB from 20 regions of the country used this app, and most of them (87.2%) were on TB treatment.

The users of Onelmpact reported 273 cases. 30% of the users of this digital solution reported economic burden (transport) related to TB treatment. Also, people affected by TB claimed inaccessibility to social support services, felt loneliness, isolation, stigma, and discrimination. They also claimed **inaccessibility to social support services, loneliness, isolation, facing stigma, and discrimination.**

Close to one-third (30%) of the users faced problems related to **getting social allowance/invalid status**, and 7% reported **stigma**.

It is very important to train users and introduce the new feature example, in TB treatment centers.

Read more about the community-led monitoring using the Onelmpact smartphone app from the [TB Europe Coalition website](#). Also, watch the video that gives a good overview of the **Onelmpact Azerbaijan** mobile application features as well as of benefits and possibilities it brings for people affected by TB.

## Countries practice. Onelmpact Ukraine

**TBpeopleUkraine** was one of the first in the region to implement the application in Ukraine and achieved its spread throughout the country.

- Start of Onelmpact implementation in 2019.
- Since 2020, all districts of the country are covered.
- People with tuberculosis have the opportunity to report barriers and violations of their rights, to receive the necessary advice.
- The system serves to develop an evidence base, which is subsequently used by government agencies when making systemic decisions in the field of TB.
- Onelmpact covers 10% of people with TB.
- During the operation of Onelmpact, 3000 messages were received about various barriers.



- Thanks to the appeal through OnelImpact, people with TB can also receive material support in the form of food certificates (more than 400 issued), medicine for stopping the side effects of anti-tuberculosis treatment (550 calls), etc.

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*"Thanks to the OnelImpact application in Ukraine, in 2020 alone, more than a thousand people with tuberculosis were able to receive support, assistance, and maintenance in overcoming the barriers they faced. This helps a lot to maintain adherence to treatment, because every person affected by the problem of tuberculosis may face some difficulties. And in this case, they should be able to communicate their needs or concerns." - says Olya Klymenko, Chair of the Board of TBpeopleUkraine and Head of the Steering Committee of the "Stop TB Partnership. Ukraine", - "To make this possible, we did a lot of preparatory work before launching the application. First, we needed to raise awareness among people with tuberculosis about their rights. Secondly, we trained and convinced physicians that with OnelImpact we planned to build evidence for positive systemic change, not complaints. We also established an effective partnership with the responsible state authority, the Centre for Public Health of the Ministry of Health of Ukraine, which supported our initiative and contributed to the fact that local medical institutions became more open to cooperation related to the use of OnelImpact. In addition, we have combined our efforts to quickly respond to information coming through the application about the problems of people with tuberculosis. Such achievements are, of course, the result of teamwork, and we thank to all partners for their interaction."*

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According to the **TBpeopleUkraine** the initial data analysis showed that 52% of people had barriers to social services (additional financial and food assistance for people who have lost their jobs, drug delivery, treatment of comorbidities diseases, transportation, etc.), 41% experienced barriers in accessing medical services (including access to treatment and diagnostics, side effects therapy, the quality of services provided at medical institutions, etc.), 4% of people experienced stigmatization and 2% reported about rights violations.

TBpeopleUkraine **helped to cover the cost of diagnostics, fare expenses, food provision, and purchasing medications to manage complications related to TB treatment.** OnelImpact Ukraine app implemented by the TBpeopleUkraine allows the users to take a survey on the impact of COVID-19 on the TB treatment since spring 2020. Also, this new functionality allows the users to report on **barriers related to COVID-19**.

The use of this app **has grown rapidly in Ukraine**. TBpeopleUkraine is actively developing it and at the same time helping to solve the problems registered by its users related to discrimination, access to and quality of treatment, management of side-effects treatment, and other problems.

For wide access to patients undergoing hospital treatment, it is planned to install stationary IBox devices with access to the OnelImpact mobile application at key TB institutions.

In addition, it is planned to create a network of paralegal assistance in all the regions of Ukraine to quickly respond and resolve legal barriers for people with TB. For this purpose, trainings for activists and employees of regional secondary legal aid centers will be held to train them in paralegal assistance and the specifics of working with complaints from people with TB with participation of legal experts from the Free Legal Aid Centers.

Further information on the implementation of OnelImpact in Ukraine and how it can be used in **TB advocacy** work can be found on the **TB Europe Coalition** website.



# CONCLUSION

The following brochure is developed by TB Europe Coalition within the framework of the Strategic Initiative "Community, Rights and Gender Strategic Initiative - Meaningful Engagement and Capacity Development of Key and Vulnerable Populations", and will be useful for Civil Society Organizations and the communities affected by TB.

The document helps to understand the practical use of the main assessment tools developed by the STOP TB Partnership in the field of TB control, among which the main place is taken by the TB stigma assessment tool, the TB Community, Rights and Gender (CRG) tool within human rights based evaluation and focused on the needs of people affected by tuberculosis as well as Community-Led monitoring of the TB response, using the OnelImpact digital platform.

It is important to know that the Global Fund urges countries to include these activities into grant applications in order to empower CSOs and TB communities to collect and further use up-to-date evidence base and therefore to improve the quality and investment efficiency into TB services (for more details, see the [Applicant Handbook 2020-2022](#)).

The logo for the TB Europe Coalition, featuring the text "TB Europe Coalition" in a white, sans-serif font. The text is centered and positioned above a stylized graphic of overlapping, semi-transparent squares in various shades of blue and teal, which form a cloud-like shape. The background of the entire page is a solid blue color with a subtle gradient, and a thin yellow horizontal bar is visible at the top.

**TB Europe Coalition**