

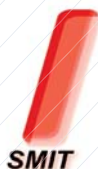


TB REP

ACHIEVEMENTS IN PROMOTING PEOPLE-CENTERED TB CARE:

SUCCESSES OF CIVIL SOCIETY ORGANIZATIONS WITHIN THE TB-REP PROJECT

(2016 – 2018)





TB REP

ACHIEVEMENTS IN PROMOTING PEOPLE-CENTERED TB CARE:

SUCCESSSES OF CIVIL SOCIETY ORGANIZATIONS WITHIN THE TB-REP PROJECT

(2016 – 2018)

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ABBREVIATIONS

Alliance	Alliance for Public Health, Ukraine
ACSM Strategy	Advocacy, Communication and Social Mobilization Strategy
AIDS	Acquired immunodeficiency syndrome
CCM	Country Coordinating Mechanism
CSO	Civil society organization
DR-TB	Drug-resistant tuberculosis
DS-TB	Drug-sensitive tuberculosis
EECA	Eastern Europe and Central Asia
GF	Global Fund to Fight AIDS, Tuberculosis and Malaria
GFMA	Georgian Family Medicine Association
HCF	Healthcare facility
HIV	Human immunodeficiency virus
MDR-TB	Multidrug-resistant tuberculosis
NGO	Non-governmental organization
NTP	National Tuberculosis Care Program
PAS Center	Center for Health Policies and Studies, Moldova
PHC	Primary health care
RR-TB	Rifampicin resistant TB
TB	Tuberculosis
TBEC	TB Europe Coalition
TB-REP	TB Regional EECA Project on Strengthening Health Systems for Effective TB and DR-TB Control
UN	United Nations
WHO	World Health Organization
XDR-TB	Extensively drug-resistant tuberculosis



Tuberculosis (TB) especially multidrug resistant TB (MDR-TB) is one of the most serious public health concerns in the WHO European region.

In 2016, there were an estimated 10.4 million new TB cases worldwide. An estimated 1.7 million people died from TB, including nearly 400 000 people who were co-infected with HIV.¹

MDR-TB poses a particular challenge in WHO's European Region, which has nine of the world's 30 highest MDR-TB burden countries.²

Currently, countries in the region implement a number of intervention measures related to new methods to diagnose TB, increasing access to new TB drug regimens and improving infection control practices.

With technical support, many of these countries are increasing their efforts to reduce hospitalization rates by improving patient-centered outpatient services, decreasing the number of TB beds and the unnecessarily long duration of hospital stays, reallocating TB budgets accordingly, and reassigning staff in hospitals to overall pulmonary and primary health care.

However, it is not possible to reduce the burden of tuberculosis without shifting the paradigm of national TB responses, and adapting TB care to people's needs, transitioning to people-centered TB care models, ensuring interagency and interdepartmental cooperation and eliminating all forms of stigma and discrimination against people affected by TB.

People-centered care should take into account not only medical care, but also social and personal needs of people and the local social, structural and cultural factors.

It is not possible to implement people-centered TB care without actively involving non-governmental organizations and people

affected by TB, without awareness-raising campaigns, integration with primary health care, support from decision-makers, strengthening the referrals between the providers of medical and social services and launching the mechanisms of funding reallocation.

To overcome these issues and reduce the TB burden in the region, the TB Regional EECA Project (TB-REP) on Strengthening Health Systems for Effective TB and DR-TB Control (TB-REP), funded by the Global Fund to Fight AIDS, Tuberculosis and Malaria (GF) is currently being implemented.

TB-REP is the first project in Eastern Europe and Central Asia (EECA) aimed at reducing the burden of TB and ending the spread of multidrug-resistant forms of TB in EECA countries through health system strengthening, increasing political commitment, building the capacity of civil society and accelerating the transition from inpatient and sanatorium treatment of tuberculosis to outpatient care models.

Principal recipient of the GF grant within this Project is the Center for Health Policies and Studies (Moldova) here in after — PAS Center, an organization that has a wide ranging portfolio of public health programs, management of TB programs and over 10 years of implementation experience of various projects and programs to fight TB, including in the role of Principal Recipient for country TB grants starting in 2010.

Within TB-REP, the PAS Center oversees implementation of regional activities to transform health systems based on the people's needs in 11 countries of Eastern Europe and Central Asia: Armenia, Azerbaijan, Belarus, Georgia, Kazakhstan, Kyrgyzstan, Moldova, Tajikistan, Turkmenistan, Ukraine and Uzbekistan. Thanks to this project, the interest of civil society organizations and communities affected by TB have increased their

¹ Global tuberculosis report 2017. World Health Organization. https://www.who.int/tb/publications/global_report/gtbr2017_main_text.pdf

² Global tuberculosis report 2016. World Health Organization. <http://apps.who.int/medicinedocs/documents/s23098en/s23098en.pdf>

attention and interest to actively take part in transformation of TB services and health systems overall. The main technical lead is WHO Regional Office for Europe.

Project implementers included a wide range of partners, including the TB Europe Coalition (being represented by the Alliance for Public Health (Alliance)), the European Respiratory Society, the London School of Economics and Political Science, the London School of Hygiene and Tropical Medicine, and the Stop TB Partnership.

During the period of its implementation (2016-2018), the project allowed increasing the political commitment to TB and MDR/XDR-TB response through regional cooperation and knowledge sharing to improve implementation of the National TB Care Programs (NTP); developing evidence-based practices in effective TB service provision systems to implement people-centered approaches and innovative models of services, as well as offering technical assistance to implementing the people-centered model of care and efficient funding mechanisms in the TB response.

However, the project would not be successful without advocacy, which was aimed at:

- Strengthening and developing the networks of people affected by tuberculosis to improve the efficiency of their advocacy efforts and engage them in decision-making processes;
- Developing cross-sectoral partnerships with wide participation of stakeholders to ensure the transition to people-centered care;
- Raising awareness of the advantages of outpatient TB care and reducing stigma against people affected with TB;
- Promoting social contracting mechanisms to promote further involvement of civil society in the delivery of TB services as well as sustainability of such services.



Civil society organizations are the driving force of advocacy processes and changes at national and regional levels. Within the TB-REP Project, their efforts were coordinated and supported within the civil society component.

This component was successfully implemented by the TB Europe Coalition — regional network of human rights-based civil society organizations and private individuals from all over the WHO European region, including the countries of Western and Eastern Europe, Caucasus and Central Asia.

TBEC strives to reinforce the role of civil society within the regional TB response and ensure that political and financial commitments are made to eliminate TB.

The role of TB-REP partner within the civil society” component on behalf of TBEC was delegated to Alliance.

Alliance is making a significant impact on the epidemics of HIV/AIDS, tuberculosis, viral hepatitis and other socially dangerous diseases in Ukraine. In cooperation with state partners and civil society organizations, it provides financial and technical support to programs, covering over 250,000 representatives of most vulnerable populations, which is the highest coverage indicator in Europe.

Alliance implements its project component through consultations, coordination, and implementation of the country monitoring and support missions and through documenting the best practices of local implementing partners in each of the countries.

This publication presents advocacy achievements of 11 civil society organizations implementing the Project. The information presented will allow civil society representatives to adopt the successes of their colleagues for further implementation in their own countries.

SUCCESS STORIES
IMPLEMENTED BY
THE CIVIL SOCIETY PARTNERS
WITHIN THE TB-REP PROJECT

IN 11 COUNTRIES





AZERBAIJAN

ORGANIZATION

“Sağlamlığa
Xidmət”



PROJECT

“Strengthening capacity
of CSO and media partners
on sustainable advocacy
for transition to an outpatient
model of TB care”

ABOUT THE PROJECT

Project activities are focused on supporting cross-sectoral partnerships between governmental and non-governmental stakeholders and strengthening the network of people affected by TB as well as collaboration with members of the Parliament Committee for Health.

In the first year of project implementation, the main achievement of the civil society partner was creating video materials based on a case study of the barriers and needs in TB care. For the first time in the last ten years, an awareness-raising film about tuberculosis “A Winter Breath” was released in Azerbaijan within the TB-REP project. This video was aimed at overcoming stigma against people affected by TB and sharing information on introducing people-centered models of TB care and the importance of adherence to treatment. The main character of the video was a woman as it is women who are most exposed to stigma and self-stigma.



Elchin Mukhtarli

Director, NGO
“Sağlamlığa Xidmət”,
TB-REP Project Coordinator
in Azerbaijan

”

In the last three years, civil society in Azerbaijan has made great progress as a result of the TB-REP Project. It has changed the perceptions of national civil society organizations concerning response to TB and helped them see their role in a more strategic and broader way. Today, civil society organizations together with people affected by TB, are advocating at a high level to resolve TB issues, meeting with parliamentarians and other decision-makers and playing a significant role in the national TB response.

”

Implementing a people-centered TB care model through building and strengthening partnerships between civil society organizations and MPs

Three years ago, stigma against people affected with TB in Azerbaijan was extremely high. In particular, it was confirmed by the results of the study carried out in two major cities at the start of the TB-REP Project. A survey was conducted among people affected by tuberculosis and health workers in TB clinics and primary health care institutions. 99% of respondents from among people affected by TB said that they tried to hide their diagnosis.

Furthermore, the study showed that barriers to the effective provision of TB services included insufficient awareness of the importance of timely diagnosis and the advantages of a people-centered TB care model.

Based on the survey results, the available project data and analysis of the statistical information about TB services, the Azerbaijan TB-REP team developed an intensive advocacy plan. Having started its activities in 2016, the implementing

partner made great progress in implementation of the people-centered TB care model.

One of the most important areas of advocacy effort was establishing partner relations between civil society representatives and parliamentarians. After all, parliamentarians are the ones who play a vital role in overcoming TB by developing policies and allocating budget funds. In addition, parliamentarians can raise awareness of their voters regarding the disease and make a significant social impact for overcoming stigma against people affected by TB.

To improve efficiency, build their capacity and increase the significance of civil society in TB care, civil society organizations (CSOs) working in the area of TB formed a Coalition. For the first time, civil society representatives took part in public hearings organized in the Parliament of Azerbaijan. Before that, there were numerous meetings and trainings held for members of the TB Azerbaijan Coalition (TBAZC). Also, five months before the public hearings, CSO members held a number of meetings with MPs, at which they raised the most vital issues regarding the national TB response. Thus, the TB agenda was effectively brought to the highest political level.



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ACHIEVEMENTS IN PROMOTING PEOPLE-CENTERED TB CARE:

Members of the community of people affected by TB also participated actively in the meetings with the MPs. The group of people affected by TB was also supported to ensure their representation in the Country Coordinating Mechanism. Support was provided to bring the community into TB-related decision-making processes and to ensure active participation of

project, as well as making and distributing video materials about TB created a good information framework, so that now decision-makers are much better informed about the key issues related to TB. Such awareness helps civil society representatives hold meetings and negotiations with decision-makers more effectively.

Meetings with MPs organized by the TB-REP team in Azerbaijan are conducted in a friendly manner and aimed at raising the awareness of parliamentarians on vital issues faced by civil society organizations in their TB response efforts. As a result of building partnerships with MPs, TB Azerbaijan Coalition got significant support from them in implementing their project activities. In particular, the Coalition held a number of meetings with local authorities in several districts with high levels of TB incidence and carried out an awareness-raising campaign on TB prevention. Videos prepared within the TB-REP Project are shown on national TV channels. Parliamentarians supported the TB awareness-raising campaign on their pages in social media. They share information about the disease, about the need to diagnose it and prevent stigma against people affected by TB with their numerous subscribers. In communication with MPs, a special focus is made on protecting the rights of people affected by TB and providing them with social benefits and support.

the community in relevant activities. Using any opportunity available, community members met Azerbaijani MPs and other decision-makers at various events and conferences, drawing their attention to the issue of TB. Apart from that, community members often spoke to mass media at public events. This, in turn, raised awareness of the general population of TB and reduced stigma against people affected by TB, teaching people not to be afraid of TB, but to diagnose it as early as possible and treat it effectively. Cooperation with journalists as part of the

In Azerbaijan, parliamentarians continue to be actively involved in raising public awareness on the issues of TB and in accelerating implementation of people-centered TB care. Meanwhile, the TB-REP team plans to focus its future efforts on developing and maintaining partnerships with MPs to promote rapid transition to people-centered TB care and on further involving parliamentarians in the TB response. Political will can help the Project achieve sustainable results!





ARMENIA



**Anahit
Harutyunyan**

*President,
Social NGO
"Positive People
Armenian Network",
TB-REP Project
Coordinator in Armenia*



The most valuable thing we have achieved thanks to the TB-REP project is founding the civil society based monitoring group. We have been able to improve our partnership and build up the capacity of civil society to perform this monitoring.



ORGANIZATION

Social NGO
"Positive People
Armenian Network"



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PROJECT

"Changes are Possible!
Act Now!"

ABOUT THE PROJECT

The goal of the project is supporting transition to a quality-assured people-centered TB care model in Armenia.

As part of the project implementation, an assessment was performed on compliance of the National Tuberculosis Program (NTP) to the Tuberculosis Action Plan of the WHO European Region 2016–2020, with in-depth interviews conducted with people affected by TB concerning their experience of TB care. Based on these materials, an advocacy strategy was developed, which was presented to the Country Coordination Mechanism (CCM), so that all stakeholders in the country could familiarize themselves with the strategy. The strategy covers the issues related to the main goal of TB-REP – accelerating introduction of TB outpatient care –, in particular improving services in outpatient facilities, reducing stigma and ensuring the access of civil society organizations (CSOs) to financial support in the course of transition from GF grants to national funding.

Assessment of the needs of people affected by TB as a component of building up capacity of communities of people affected by TB, for advocacy activities

Despite the fact that the people-centered TB treatment model has been implemented in Armenia since 2015, and the existing outpatient offices have been upgraded and improved, there are still substantial gaps in the TB care system. These include insufficient attention to the needs of

people affected by TB and the low level of their involvement in any changes.

One of the reasons for that was the lack of understanding at national level of barriers related to the transition to TB people-centered care models. To elaborate a determined advocacy policy aimed at removing the barriers, a study of needs of people affected by TB aiming to identify problems related to the transition to TB people-centered care models was conducted under the TB-REP project. At the same time, the goal of the advocacy work was to deliver the results of the assessment to decision-makers and to use these results to develop specific plans for implementation of people-centered care.

To assess the needs, a study program was developed and, after consultation with stakeholders and project donors, finalized together with the Ethical Committee of National Center for AIDS Prevention.

TB-REP grantee, Social NGO “Positive People Armenian Network” organized two meetings with people affected by TB to thoroughly discuss questions in the questionnaire. Participants’ suggestions were included in the questionnaires

as appendices. A group of interviewers were recruited from among the staff of the organization, as well as from among people affected by TB.

The survey was conducted in 4 regions of Armenia (Ararat, Lori, Gegharkunik, Syunik) and Yerevan, which feature the biggest numbers of people with TB. It allowed identification of the strongest and weakest points in the field of TB treatment. Structured interviews and expert interviews were used as the research method. Assessment of needs covered 240 persons affected by TB and 12 experts. Statistical significance was 5%.



The questionnaire included 5 main topical categories: TB diagnostics, TB treatment, treatment of co-infections, psychosocial support, and human rights.

The study revealed that 62.9% of respondents had seen their local doctor in an outpatient department, and 70.8% of them had been referred to a TB dispensary for inpatient treatment. 89.2% of people affected by TB reported that they had received consultations on TB before diagnosis, and only 10.8% stated they had not. 76.2% of respondents were satisfied with the information they had received during their consultation.

From the very beginning, 16.2% of respondents received only outpatient treatment and 5.4% only inpatient treatment. 78.4% were first treated at a hospital, and later in outpatient mode. People treated in hospitals mentioned poor living conditions and the length of treatment as negative aspects.

Talking about positive aspects of outpatient treatment, people mentioned not being isolated from society during treatment; negative aspects included the need to visit health care facilities daily to take TB drugs. 21.7% of respondents stated that they preferred inpatient treatment, and 66.2% favoured outpatient treatment.

The respondents were also given the opportunity to submit proposals for improving the TB care system, and these included: using more effective equipment, providing individualized conditions to people affected by TB, and creating opportunities to communicate with people who had experienced TB treatment.

Considering the political changes in Armenia, it was important that the Director of the National TB Center and Deputy Minister of Health who is also country coordinator of the TB response, knew the results of the study. Data analysis identified several factors in the work of the



National TB Center that required improvement. In particular, the quality of patients' diet needed improvement. The new Director has taken note of that, and patients already claim that their diet has improved.

Study data analysis also helped form action plans for the next stage of implementation of the project "Changes are Possible! Act now!". In particular, it was decided to implement community-based monitoring, and this happened from August 2018 by the project grantee and is aimed, in particular, at detecting cases of interrupted treatment.

Furthermore, results of the assessment were presented to the general public and all stakeholders at a press conference. It is expected that the data will help focus attention on introducing care centered on the needs of TB-affected people and will strengthen the advocacy capacity of the community of TB-affected people.



BELARUS



Natalya Kryshchafovich

Chair, Republican Public Association "Defeat TB Together",
TB-REP Project Coordinator in Belarus

“ Before TB-REP, they used to say ‘we want to hear the voice of the people affected by TB’. Now the voices of such people sound loud and clear on various levels, from the UN meeting in New York to any region of the Republic of Belarus, and this voice influences decision-making at different levels. ”

ORGANIZATION

Republican public
association “ Defeat
Tuberculosis Together”



PROJECT

“ Outpatient
treatment of
tuberculosis -
time for us, money
for the country,
health for everyone”

ABOUT THE PROJECT

The goal of the project is to improve access to an outpatient model of TB diagnostics and treatment.

Throughout project implementation, a wide range of stakeholders were consulted to promote the strategy of transition to people-centered outpatient care. There was work on ensuring complementarity of the Global Fund national grant application for 2019-2021 and necessary steps for switching to quality-assured people-centered care. Also, support for the creation and start of operations of the first national group of people affected by TB was provided. In addition,

in 3 oblasts (regions), innovative “forum theater” events were held to reduce the stigma against people affected by tuberculosis.

A distinguishing feature of activities of the partner in Belarus is their close cooperation with the National Office of the WHO.

Project activities were also aimed at building up the capacity of civil society organizations and developing partnership for sustainable work on promotion of transition to outpatient care for the main TB-affected populations, as well as reducing stigma and discrimination.

Using forum theaters to raise awareness of tuberculosis and overcome stigma against people affected by TB

Stereotypes, myths and misconceptions regarding people affected by TB lead to public stigmatization and discrimination of such people, significantly impeding implementation of people-centered TB care models in the country. One of the most serious misconceptions is that there is a risk of being infected by people receiving outpatient treatment. This stereotype leads to social isolation of people receiving outpatient treatment and makes primary health care doctors and social workers biased and unwilling to work with them.

In order to resolve this problem and raise awareness of the disease, the Republican Public

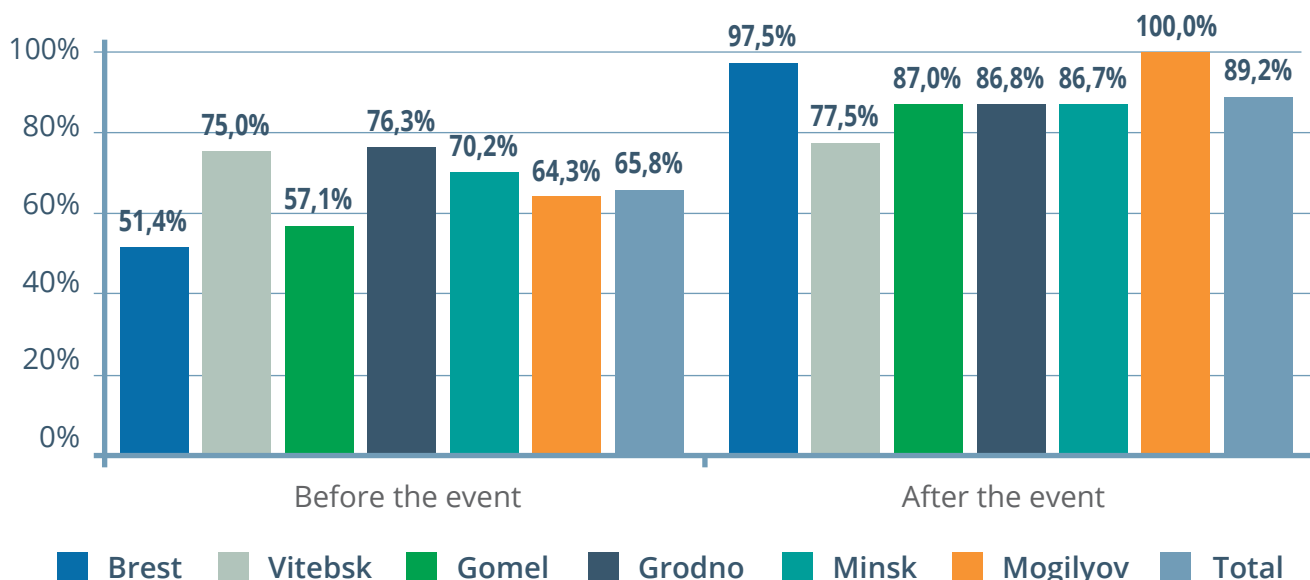
Association “Defeat TB Together”, acting as the TB-REP project in Belarus, used an unconventional innovative approach and, together with partners, held a cycle of preventive events using a “Forum Theater” approach.

These Forum Theater-like interactive events involved feedback from the audience based on pre-planned everyday situations, controlled by a moderator. These situations had been prepared during a dedicated master class and further developed by theater and prevention experts. The scenarios used 2 key topics: TB is curable, and a person receiving outpatient TB treatment poses no danger to society.

To evaluate the impact of these activities, for 9 months from June 2017 to February 2018, “Defeat TB Together” measured society’s awareness and level of tolerance to people affected by TB. The evaluation involved 250 guests from Forum theater events in Brest, Vitebsk, Gomel, Grodno, Minsk and Mogilev, who completed a questionnaire before and after the events. Questions in the questionnaire were developed so as to detect changes in people’s knowledge of tuberculosis, as well as their attitude to people affected by TB.

Results of the evaluation show that the level of knowledge and tolerance after the events increased by 28.9%. It shows the Forum Theater effectiveness in achieving the goals set. Changes

FIGURE 1. Distribution of “Yes” answers to the question “Is TB curable?” by cities before and after the event





in knowledge and attitude differ in different age groups of participants. The most notable intensive change (38.1%) occurred in the 15-29 age group, and the lowest (7.1%) in the group of people above 60. It should be noted that in people above 60, the initial levels of knowledge and tolerance were the highest (53.5%) compared to other age groups (24% among youths and 28.9% in middle-aged people). It is probably linked to the fact that older people, on the one hand, have more experience of communication with people affected by TB and higher tolerance (possibly shaped by their

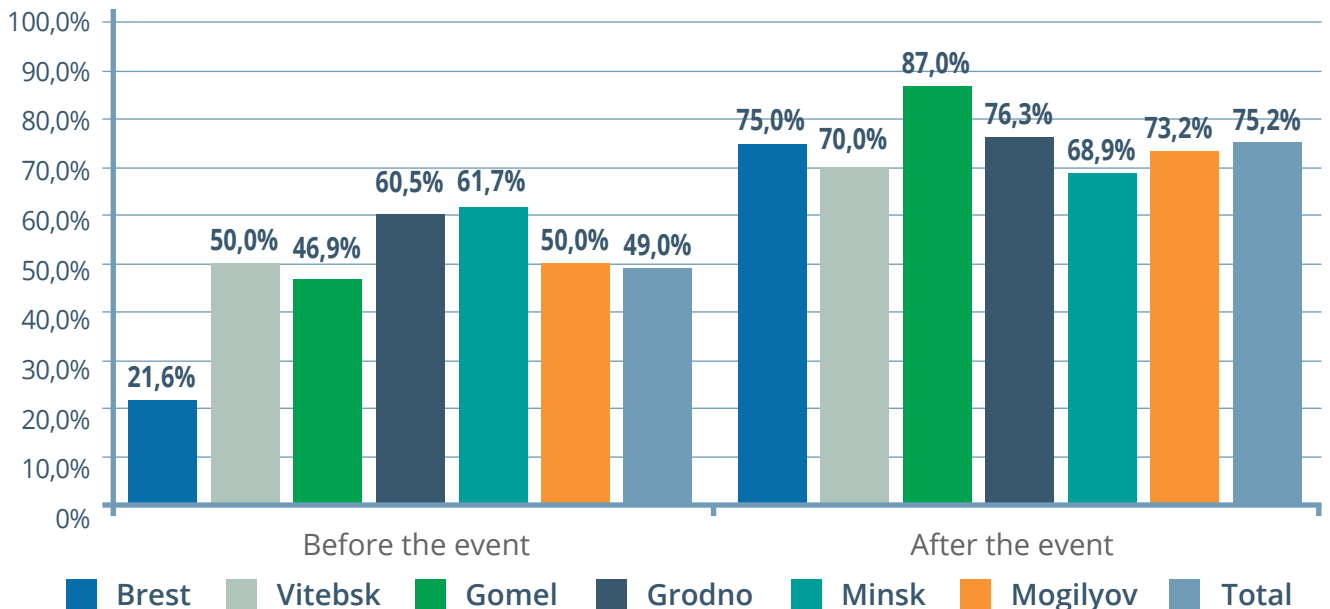
life experiences), and, on the other hand, are less willing to change their knowledge and values.

There is also a notable connection between professional training and the level of change. Indeed, in Gomel, Vitebsk, Grodno and Mogilev the events were attended by personnel from Territorial Social Service centers, which influenced the distribution of responses in the age categories of 15-29 and 30-59. Apparently, their professional background and the social nature of their work allowed them to demonstrate a higher level of knowledge about TB and tolerance toward people affected by TB than students in Minsk and Brest.

As the 15-29 group is the most willing to change their knowledge and attitude, using the Forum Theater technology for prevention work in youth (both students and workers) is relevant and effective.

Since the levels of knowledge and tolerance of the audience after the events rose by almost one third (28.9%), the practice of forum theatre can be considered an innovative and effective prevention activity, improving people's knowledge of tuberculosis and helping to overcome the stigma of people affected by TB, and to fight stereotypes and misconceptions about TB. This technology should be further used in advocacy activities related to fighting tuberculosis.

FIGURE 2. Distribution of "No" answers to the question "If a person leaves the hospital, but continues to take drugs daily, can he transmit TB to another person?" by cities before and after the event





GEORGIA



Irine Karozanidze

*Director, Georgia Family Medicine Association,
TB-REP Project Coordinator in Georgia*

” Successful TB care outcomes can only be achieved if services are delivered closer to communities. TB specialists, primary care providers and community based organizations should unite their efforts to comprehensively address the needs of TB patients and their families. ”

ORGANIZATION

PROJECT

Georgia
Family
Medicine
Association



Strengthening
Outpatient TB Care
model in Georgia

ABOUT THE PROJECT

The goal of the project is to improve access to and the coverage of outpatient TB care services.

The project promotes outpatient treatment models for people with drug-susceptible tuberculosis and multidrug-resistant tuberculosis through advocacy for more active involvement of primary health care institutions and ambulatory facilities in TB diagnosis and follow-up.

During the first year of implementation of the project, a strategy of advocacy for an outpatient TB treatment model was developed, and a number of topical and informational high-level meetings were conducted to advocate for transition to provision of TB people-

centered care and building up capacity of TB-affected people and their representation in high-level decision-making bodies. In the second year of the project, Georgia Family Medicine Association promoted a dialogue in the country to develop the outpatient TB treatment model for Georgia. A concept of outpatient TB treatment was developed, and some of its provisions were included in the National TB Guidelines, including hospitalization criteria. Throughout the third year of the TB-REP project, Georgia Family Medicine Association (GFMA) continued technical work and advocacy activities to promote the people-centered TB care model according to TB-REP plans and the latest recommendations of WHO.

Empowering the community of people affected by TB for their greater involvement in the national TB response

One of the main problems in terms of overcoming the TB epidemic, especially in the context of implementation of outpatient care models, is the lack of adherence to treatment. This is caused by absence or insufficient level of psychosocial support, as well as certain barriers to accessing outpatient treatment.

Family doctors play a noticeable part in resolving this problem in Georgia. Under the TB-REP project, the Georgia Family Medicine Association (GFMA) since 2016 has been establishing close partnership with the community of people recovering from tuberculosis to ensure involvement of the most vulnerable and affected

groups in advocacy for improving access to outpatient TB treatment in Georgia. Several years ago GFMA joined their efforts with the Georgia Patients' Union (GPU), a young entity established by people affected by TB and their families. GFMA engaged GPU members in technical and policy discussions about people-centered TB care to ensure that the voices of people affected by TB were heard by decision-makers.

GPU representatives Nikoloz Mirzashvili and Lali Janashia served as facilitators at all thematic and high level meetings organized within the TB REP program. Senior technical advisors of GFMA had several individual meetings to assist with preparation and address possible technical challenges. Thanks to GPU connections and efforts, GFMA were able to bring people affected by TB, family medicine practitioners and primary health care managers from public and private institutions, as well as representatives of the Ministry of Labor, Health and Social Affairs and the National Center for Disease Control (NCDC) and Public Health together around the table for a very open and constructive dialogue on the needs of people affected by TB. This served as a great icebreaker and stimulated interest by all parties in further collaboration.

In order to enhance involvement and build up capacity of groups of people affected by TB, GFMA has been supporting inclusion of GPU representatives' speeches in national and international forums. As a part of development of the outpatient model, GFMA, in collaboration with their partners, have formulated a clear set of functions for representatives of TB-affected people in TB case detection and adherence support. Also, the TB-REP grantee advocated actively for inclusion of peer counselling as a service within the National TB Program. This idea was further supported by the National Center for Disease Control and Public Health through the Global Fund TB program. As a result, the pilot community-based adherence support program was launched



in July 2017 with GPU providing treatment adherence counselling services for people with MDR-TB in outpatient settings in five regions.

Within this project, peer to peer educators/people affected by TB, social workers and psychologists work together to identify and address potential barriers to treatment adherence. Six adherence teams were composed and trained in TB counselling, ethical issues, confidentiality, informed consent, and infection control. They used a unified case management protocol elaborated with professional input from psychologists and social workers, and with contributions from people affected by TB. A Memorandum of Understanding was signed with TB service facilities to ensure close communication and collaboration with health-care professionals.

By June 2018, over 220 persons with MDR-TB had received peer-to-peer adherence counselling which proved to be especially significant for hard-to-reach groups, including homeless people. The treatment was completed by 45 individuals while another 155 people are still on treatment. Only 20 individuals with MDR-TB were lost to follow up (moved outside Georgia, died, or were imprisoned). In several cases, adherence teams managed to find and engage in treatment those people who had previously been lost to follow up. The loss to follow-up within 6 months of treatment amounted to less than 6%, while the national baseline indicator was 12%.

A number of consultative meetings were arranged under the TB-REP project to analyse early implementation experience and assist GPU and other implementing partners in advancing this model. Social vulnerability, anxiety/depression and substance abuse were named as the most significant barriers to treatment adherence.

Based on this experience, NCDC decided to provide these services countrywide. GFMA will further support GPU and other civil society actors under the umbrella of the Georgia TB Coalition.



Another good practice was holding a contest among outpatient clinics providing TB-related services. The best TB outpatient clinic is given the GPU award, which encourages efforts to ensure high quality of TB services in a people-friendly environment.

Georgia's experience clearly proves that collaboration between well-established professional groups and patient organizations, which often lack experience and institutional capacity for independent operations, is mutually beneficial. GFMA effectively transferred its expertise of outpatient care service delivery and high level advocacy experience to GPU members. In turn, it received excellent understanding of the needs and expectations of people affected by TB, which allowed formulation of a robust advocacy strategy for transition to people-centered outpatient TB care.



KAZAKHSTAN



Nurali Amanzholov

*President, Alliance of Legal Entities
"Kazakh Union of People Living with HIV",
TB-REP Project Coordinator in Kazakhstan*

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In Kazakhstan, the TB-REP project enabled improved involvement of civil society in decision-making and better collaboration with the TB service.

”

ORGANIZATION

**ALE “Kazakh union
of people living with HIV”**



PROJECT

**Considerable increase
in participation of civil
society in reducing
the burden of TB in
Kazakhstan**

ABOUT THE PROJECT

While implementing the project, the partner – a network organization uniting many civil society organizations (CSOs) – has significantly increased civil society’s involvement in the TB response. For this purpose, analysis was undertaken of compliance of the “Plan for Comprehensive TB response in the Republic of Kazakhstan for 2014-2020” with “Tuberculosis Action Plan for the WHO European Region for 2016-2020”, especially with regard to strengthening community systems and analysis of barriers to accessing high-quality services. Partnerships were strengthened with key governmental and international organizations to strengthen their advocacy efforts. Advocacy trainings were held to build up the capacity of civil society activists in fighting the TB epidemic.

Also, efforts were made to build up the capacity of non-governmental organizations (NGOs) to receive public social order (form of social projects aimed at solving social problems, provided through the state budget) for psychosocial support and informing people affected by TB.

In Almaty and Temirtau, they organized support groups for people who do not have access to TB treatment because of not having medical insurance documents. Public awareness of the outpatient treatment model rose. Furthermore, people affected by TB were referred to partner organizations to receive social support, which, in turn, worked towards ensuring access to social support and adherence promotion.

Building the capacity of civil society organizations to receive public social contracts for providing support to people affected by TB

ECA countries are facing the forthcoming departure of the donor funding from Global Fund that has enabled so many achievements in the TB response over recent years. Now, sustainability of the changes in TB response will to a great extent depend on building an effective public financing system and the quality of transition to it.

One of the important elements of state support is implementation of public social procurement. Legislation of Kazakhstan provides for TB-related state funding of civil society organizations. However, so far only a few NGOs have managed to receive such funding. In the first place, the reason is lack of knowledge of both relevant legislation and of people-centered TB services.

To solve these problems, Kazakhstan Union of PLWH, an association of legal entities, having studied the legal framework, developed guidelines on receiving social contracts from the state for NGOs.

The guidelines contain step-by-step recommendations for a uniform approach to public social procurement. They were developed to improve the understanding of both public officials and NGO staff. The guidelines use the experience of NGOs in Kazakhstan and describe requirements, procedures and mistakes that have occurred during the processing of social procurement.

The guidelines for NGOs on applying for social procurement of people-centered TB services were first presented at a working meeting of partners on 31 May 2018. Recommendations provided by partners and personnel of the TB service in the course of the discussion were then included in the document.

On 29 June 2018, the algorithm and mechanisms specified in the guidelines on applying for social procurement and implementation of the services for NGOs were presented. In addition, representatives of civil society organizations were trained on



receiving social orders from the state and on an algorithm for applying for such orders.

Holding the above events helped to build the capacity of NGOs from 12 towns. They involved leaders of the community of people affected by TB. The events allowed identification of the following problems: The TB service has not sufficiently developed technical specifications for TB-related application and in future it is necessary to advocate for adoption of intra-agency regulations concerning responsibilities, punishment and incentives in the field of detection of TB patients involving NGO staff.

In the near future, it will be possible to track the total number of NGOs who were able to receive state funding via this mechanism. One of the results of these activities is the Memorandum of Cooperation signed between the Community Fund “Answer” and Ust-Kamenogorsk town TB dispensary. It is the first step in joining efforts for writing an application to receive a social order from the state.

Kazakhstan Union of PLWH also provides technical support to NGOs in forming and promoting application under state social procurement procedures to provide social support to TB-affected populations.



As a result, the activities conducted under the TB-REP project will become a basis for changing the policy of the state regarding public funding of NGOs in order to provide social support and informing of people affected by TB. Implementation of social procurement is a significant component of public support for non-governmental organizations, promoting development and building capacity of communities of people affected by TB, improvement of access to social support for people affected by TB and their families.



KYRGYZSTAN

ORGANIZATION

The Anti
AIDS
Association
of legal
entities



PROJECT

Kyrgyzstan without tuberculosis

ABOUT THE PROJECT

Implementation of the project in Kyrgyzstan is aimed at promoting outpatient TB care among the general public, decision-makers, medical personnel, TB-affected people and their families by providing information and explanations, as well as persuading them to take specific steps to assist the TB response.

In the first year of the project, the TB response situation in Kyrgyzstan was assessed, and meetings with stakeholders were held. This allowed identification of several needs: creating a platform of TB stakeholders for participation in national-level measures, and better involvement for people affected by TB in advocacy events. This resulted in establishing the informal National TB Platform for non-governmental organizations.

The TB NGO Platform was actively supported to strengthen cooperation among all organizations providing services, including governmental agencies and non-governmental organizations, to implement TB programs, in particular prevent TB and promote outpatient care. Capacity-building workshops were conducted as well as awareness-raising campaigns dedicated to the implementation of people-centered outpatient TB care.

The project promotes education of the general population about outpatient care with a focus on reducing TB-related stigma.



Chynara Bakirova

*Executive Director,
Union of Legal Entities
"Association of AIDS
Service NGOs of the Kyrgyz
Republic 'AntiAIDS'",
TB-REP Project Coordinator
in Kyrgyzstan*

” In Kyrgyzstan, TB-REP helped civil society to unite as a broad multi-sectoral cooperation platform, which enabled it to explain, in an understandable language, to a broad public, including primary care doctors, the economic reasons and benefits for TB-affected people of implementation of outpatient TB care models. ”

Establishment and support of the National TB Platform for further effective collaboration between civil society and stakeholders to eradicate tuberculosis and implement people-centered treatment models

Country-wide organizations quite often encounter the problem of limited coordination at national level and insufficient consolidation of activities of state, international and non-governmental organizations.

To resolve this problem and build up the capacity of non-governmental organizations (NGOs) working with TB, the National TB Platform was established in Kyrgyzstan with support of the TB-REP project.

The agreement to create a National TB Platform for NGOs (Hereafter — ‘the Platform’) to strengthen collaboration between all organizations providing TB services, was achieved after a TB advocacy workshop organized for NGOs together with the TB Europe Coalition. Following 4 meetings

of the main stakeholders and representatives of state, international and non-governmental organizations, the following core tasks of the Platform were defined: advocacy on the rights of people affected by TB, promoting adherence to treatment, building a working system of medical and social support, implementation of a people-centered approach, supporting outpatient TB care model initiatives launched by Members of Parliament, and increasing state funding of TB issues.

The Platform has organized provision of technical assistance to non-governmental organizations working in the field of TB care programs and of communities affected by TB. The Platform was also joined by the Migrant Network. Leaders of the organizations were recommended for participation in regional TB meetings in Armenia and Kazakhstan. From among Platform activists, new and alternative members of CCM were selected. Many issues important to the community have been heard by international and national stakeholders who are members of the Platform, and have been included in the country's Global Fund application.



Representatives of the Platform have developed a special questionnaire used for public monitoring visits to detect problematic regional issues, and conducted training on the application of public monitoring tools for 27 representatives of civil society. They have collected information on barriers to access to TB treatment from members of the Platform, patients who had completed or were still receiving outpatient treatment as well as their families, and elaborated recommendations for further civil monitoring of TB care services.

All in all, in the period of implementation of the project, 12 monitoring visits by project staff and Platform members, as well as representatives of local NGOs, were conducted. Before that, site visits by CCM members to the sites funded by GF took place not more than once a year, and the topics of the visit were very limited, and the patients were unwilling to communicate. Presently, the community is willing to actively promote issues related to observations of civil activists, and the patients are now more open. Information materials developed by members of the Platform during Anti-TB Month are used actively; short videos are broadcast.

In 7 regions of the country, informational campaigns were conducted with the support of local



regional administrations. A workshop for 36 participants was conducted with international technical assistance to train together regional TB and public health managers and NGO leaders to elaborate joint actions at regional level, collect recommendations and discuss them at the level of Parliament and of the leadership of the MoH and the National TB Center.

Creating a unified National Platform is a good example of effectively combining efforts, building up capacity of civil society and successful consolidation of the activities of public, international and non-governmental organizations in a country's TB response.



MOLDOVA



**Oxana
Rucsineanu**

*Vice-President,
Moldova National
Association of Tuberculosis
Patients "SMIT" (Society
of Moldova against TB),
TB-REP Project
Coordinator in Moldova*

” *The project gave us understanding that different people affected by TB have different needs. Human rights-based approaches to TB care should be implemented to make the treatment, as much as possible, effective and bearable for people affected by TB and their families.* ”

ORGANIZATION

Moldova National Association of Tuberculosis Patients "SMIT" (Society of Moldova against TB)



PROJECT

Together for a TB response

ABOUT THE PROJECT

The goal of the project is to facilitate transition to people-centered care.

Project implementation is aimed at reaching three specific objectives: presenting the people-centered TB care model to key decision-makers; increasing the political commitment for TB response through the promotion of quality people-centered care; and building the capacity of civil society organizations.

In the first year of implementation of the project, the organization reviewed national and international guidelines and policy documents concerning inpatient and outpatient treatment; for the purpose of advocacy, reports on the two following topics were prepared: 'Influence of inpatient TB treatment on the social life of people affected by TB' and 'Assessment of their satisfaction with all TB services'. The grantee also developed an advocacy strategy.

Project activities were aimed, in particular, at promoting effective involvement of community members in dealing with TB care issues. Round tables were organized to inform the general public and discuss the role of local authorities, TB services, community centers, primary health care centers, public health facilities, and social services in the provision of TB care.

The organization also worked to ensure that perspectives of people affected by TB be considered during development of the road map of country reforms, as well as to engage civil society organizations (CSOs) in the TB response.

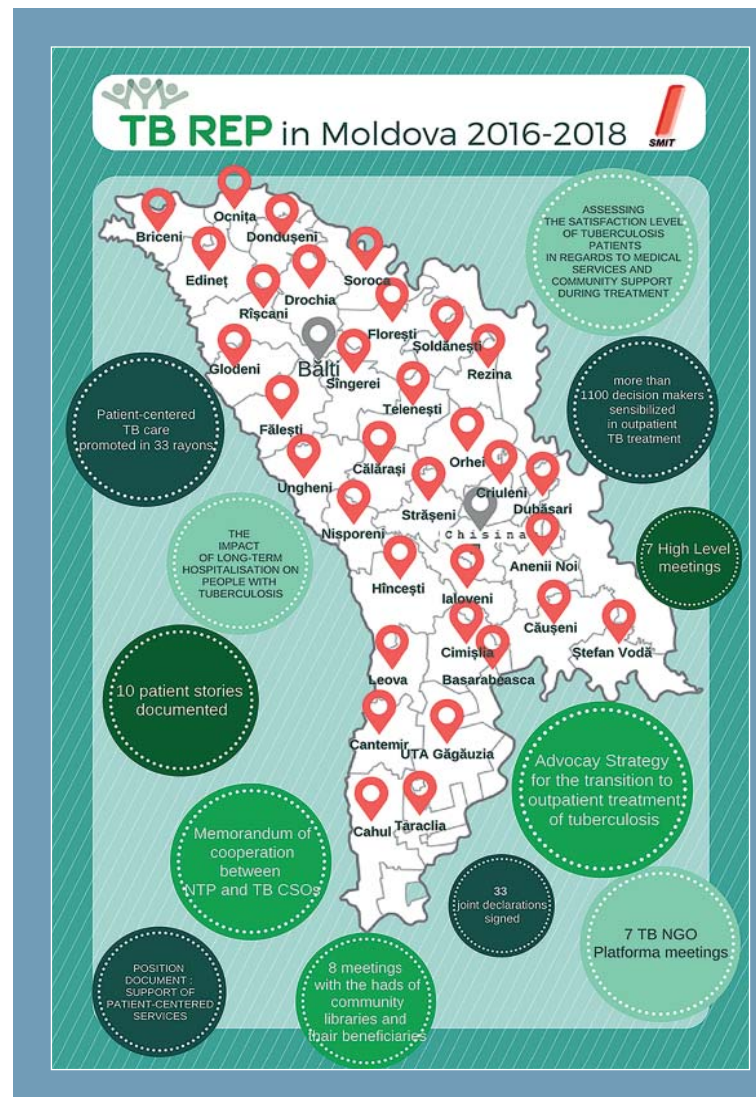
Laying foundations for the implementation of an efficient TB care model in Moldova by building communications, exploring local resources and strengthening community support

The program “Together in Tuberculosis Response” implemented in the Republic of Moldova by the Moldovan National Association of Tuberculosis Patients “SMIT” is a part of the EECA TB-REP regional program with the focus on promoting people-centred TB care.

It is widely recognised that outpatient care, especially when accompanied by appropriate social, economic and psychological support, is the best treatment option for most people with TB. It is effective, affordable, and causes the least disruption to their lives. This is confirmed also by the recent TB-REP survey of people being treated for TB: it has found that almost 70% of them preferred to receive their treatment in outpatient mode.

Civil society is the locomotive and reliable basis for large-scale implementation of people-centered TB care models. Involvement of the community of people affected by TB allows better participation in decision-making and in changing the national TB care system, which is especially important for countries with the heavy burden of a TB epidemic. This experience is well illustrated by the example of Moldova.

The Republic of Moldova has a high incidence of tuberculosis, including drug-resistant tuberculosis: in 2017, 3358 new cases were registered, which constitutes 83.3 per 100 000 population. World Health Organization rates the Republic of Moldova among the 18 countries of the European Region with a high TB burden and among the 30 countries of the world with a high burden of RR-TB, exceeding by around 3 times the average registered in the WHO EU region. The WHO estimates that the true TB incidence (ie including those people not registered by the health services) constitutes 101.0 cases per 100 000 population.





The involvement and commitment of TB civil society organizations have strengthened due to the Memorandum of Cooperation signed between civil society organisations and the National TB Program and due to consultation on the Manual regarding implementation of Standard Operational Procedures by non-governmental organisations actively involved in TB care.

Eight community libraries have been motivated, being open public platforms, to further increase community awareness and promote a friendly environment for people affected by TB and their families.

During three years of project implementation, SMIT studied the needs of and consulted over 250 TB-affected people. The data were documented and shared through two extended reports: Assessing the satisfaction level of tuberculosis patients in regards to medical services and community support during treatment and The impact of long-term hospitalisation on people affected by tuberculosis.

Advocacy and increasing awareness about innovative approaches in TB care are efficient ways to empower communication and coordination between key actors, and to lay strong foundations for the speediest implementation of people-centered TB care in Moldova. Community support and exploitation of local resources enabled implementation of measures to reduce the social, economic and psychological impact of TB treatment on patients and their families.

Using the data, SMIT advocated for TB people-centered care at country high-level meetings and in thirty-three districts of the country, and documented the concerns and suggestions of more than 1100 local decision-makers and primary health care personnel. Stakeholders signed thirty-three declarations throughout the country to further scale up joint engagement of the public, civil society and the community of people affected by TB, health care and public administration, and to endorse treatment support enabling people with TB to complete treatment.





TAJIKISTAN

ORGANIZATION

Association
Stop TB
Partnership,
Tajikistan



STOP TB
Partnership,
Tajikistan

PROJECT

Together we are strong

ABOUT THE PROJECT

The goal of the project is to promote improved access to early TB detection and treatment using the outpatient treatment model and providing TB care to key populations.

In the first year of the project, the partner reviewed the current state of outpatient care and the barriers impeding its expansion in pilot Rayons (Districts). After this review and desk analysis of documents, the grantee developed an advocacy strategy presented both at national level and in pilot rayons. The organization actively engaged community and religious leaders in creation of an innovative people-centered model — sponsorship for the benefit of TB-affected people, based on treatment outcomes, and involving businessmen, local authority officials and members of parliament/local councils in providing support to people affected by TB.

An important component of the project is assistance in creating favorable conditions in communities using campaigns to inform the general public, decrease the level of stigma against people affected by TB and reduce their social isolation. For this purpose, a media center was established under the Secretariat of Stop TB Partnership, Tajikistan. The media center started producing video and information materials based on the results of the situational review conducted in the first year of the project.



Safarali Naimov

*Executive Director,
Stop TB Partnership,
Tajikistan,
TB-REP Project Coordinator
in Tajikistan*

” *This project let us conduct a study, develop a strategy, make a plan and start action, which proves that TB can be eradicated using knowledge and providing social and psychological support to people affected by TB and their families. During the three years of project implementation I saw that charitable businessmen, religious leaders, public officials and national celebrities can be great providers of aid to the TB response, and successful examples should be further developed if we want to see the final eradication of tuberculosis.* ”

Creating a support system for a community of people affected by TB through expanding knowledge on the reduction of stigma and social isolation

Tajikistan is among 27 countries with the highest MDR-TB prevalence. Presently, about 50% of people with TB in the country are receiving outpatient treatment. Expanding coverage of the outpatient treatment model was to a great extent impeded by lack of awareness of the benefits of people-centered models, as well as of understanding of the importance of implementation of the outpatient treatment model at national level, and the lack of realization of obstacles to its large-scale implementation.

To study such obstacles, a review of the national legal framework and a sociological study of the situation with implementation of the outpatient TB treatment model involving 400 respondents were conducted. The results of the study were then used to develop, in collaboration with stakeholders, joint operational plans including TB-related activities in 4 pilot regions. In addition, the TB-REP project included activities aimed at creating community support systems.

The most successful examples of effective collaboration under the project were:

1. Implementation of the results-based sponsorship model in partnership with the Committee on Religion and Regulation of National Traditions, Festivities and Ceremony of the Republic of Tajikistan, which improved adherence indicators.

In particular, since October 2017, in five regions, 13 agreements on cooperation between the regional religious union and people with MDR-TB have been signed, with the latter now receiving monthly financial support from mosques, helping them to adhere to the treatment. Imams also work on raising the awareness of the faithful about TB symptoms and the need to be tolerant to people affected by TB.



2. Holding an essay contest dedicated to the issue of tuberculosis, among schoolchildren together with the Ministry of Education and Science of the Republic of Tajikistan and the National TB Program.

The essay contest involved 10,131 high-school pupils from 111 schools in the pilot regions of the project. It helped to significantly improve awareness of the disease and to reduce stigma aimed at people affected by TB.

3. Creating a Media Center equipped with audio and video materials and tools for TB awareness raising activities among a broad public. Operation of the Center, in time, helped to significantly improve the knowledge of TB and reduce stigma against people affected by TB.

An expert group operates at the Media Center developing and approving informational materials. Besides, Stop TB Partnership, Tajikistan have set

up collaboration with the national TV channel and professional film/theater actors for joint work on the creation and broadcasting of educational videos on TB.

4. Training 23 support group volunteers together with the National TB Program. The goals of the volunteers is to provide psychological support, promote adherence to treatment, establish communications between official health care facilities and communities, and support TB response activities.

5. Development of social entrepreneurship and supporting establishment of the car service center “Helping Hand to End TB”. This project generates income to support the continuous work of volunteers and provide direct aid to people affected by TB and their families, contributing substantially to adherence of people affected by TB.



Stop TB Partnership, Tajikistan plans to continue systemic work on strengthening and supporting the community of people affected by tuberculosis, expanding the scope of aid provided by the regional religious unions to people with MDR-TB, raising awareness of TB among the general population,

holding the annual TB essay contest among pupils, and creating social enterprises. All these measures facilitate provision of information to society about the disease and the benefits of people-centered care, and help to improve the adherence rate among people affected by TB.



TURKMENISTAN



**Ogulshirin
Karliyeva**

*National Red Crescent
Society of Turkmenistan,
TB-REP Project Coordinator
in Turkmenistan*

” *The National
Red Crescent
Society of
Turkmenistan
supported by the
TB-REP project
continued to help
expand the outreach
of programs of public
health and
disease prevention
authorities.* ”

ORGANIZATION

National Society
of Red Crescent
of Turkmenistan



PROJECT

Informing managers
and primary care physicians
about the benefits of an outpatient
tuberculosis treatment model

ABOUT THE PROJECT

The goal of the project is to increase the number of people with TB and DR-TB receiving treatment in outpatient settings by informing managers and primary health care doctors about the benefits of outpatient treatment.

Turkmenistan, where the TB REP civil society partner is the National Red Crescent Society, joined the project in 2017.

The project “Informing managers and primary care physicians about the benefits of an outpatient tuberculosis treatment model” supplements the efforts of the Ministry of Health and Medical Industry of Turkmenistan to ensure access to TB (including drug-resistant TB) care in outpatient settings through raising the awareness of managers and primary care physicians as well as patients about the advantages of the outpatient care model.

The project was implemented in 4 out of 6 regions of Turkmenistan: the city of Ashgabat and the provinces (Vilayats) of Lebap, Ahal and Mary. Ashgabat and Lebap Province had already been included by Decree of the Ministry of Health and Medical Industry of Turkmenistan (MHMIT) dated 23 March 2016 in piloting outpatient TB treatment. The MHMIT also plans to expand the outpatient MDR-TB treatment model to Mary Province, and that is why this region was included in the project. Another objective of the project is to provide psychosocial support to people affected by TB through the involvement of local communities.

Improved interaction
with managers
and doctors from
primary health
care facilities
for implementation
of people-centered
TB care models

Lack of awareness by managers and primary health care doctors, as well as TB-affected people and their families, about the benefits of modern people-centered TB care models is a serious obstacle preventing these models from being implemented. At the same time, increasing the number of people with TB (including DR-TB) who receive outpatient care means greater effectiveness of TB care, more cases achieving full recovery, lower risk of cross infection, and ensuring preservation of normal life and social conditions of people affected by TB.

One of the crucial factors for successful implementation of people-centered TB care models is awareness by primary health care managers and doctors, as well as TB-affected people and their families about the benefits of outpatient treatment.

The project of the National Red Crescent Society of Turkmenistan “Informing primary health care managers and doctors about the benefits of an outpatient TB care model” implemented under TB-REP is effective in furthering efforts of the Ministry of Health and Medical Industry of Turkmenistan to raise awareness.

The project involves a broad information campaign reaching primary health care managers and TB doctors and family doctors and delivering the message of the benefits of outpatient care.

An effective tool for informing primary health care managers and doctors is conducting round tables to discuss the benefits of patient-centered models of care.

Since the beginning of implementation of the project, 295 representatives of the primary health care system in Turkmenistan have learnt about the benefits of outpatient TB care and have acquired relevant skills. At the same time, according to estimates made by the grantee of the TB-REP project, attendees at the events have improved their knowledge and skills related to the implementation of outpatient TB care models, on the average, by 75%.





Holding the round tables also promotes closer interagency collaboration. For example, after round tables, joint work was seen to increase significantly between TB facilities and the primary care system in the districts (Rayons) of Farap and Galkynys in Lebap Provincesuch that these districts were recommended by the NTP for implementation of outpatient TB care model, and effective interaction between primary health care personnel and TB doctors was established.

In all the rayons where round tables were held, permanent phone communication with TB doctors has been arranged. This allows all stakeholders to receive any required information about outpatient treatment of patients not only from informational materials, but also through free-of-charge consultations via phone or, sometimes, in person.

Moreover, in Turkmenistan, the joint plan of activities for the TB prevention among the general population and the provision of psychological support to people affected by TB was signed between the Ministry of Health and the medical industry, the Union of Women and the National Red Crescent Society of Turkmenistan.

The joint plan is designed to assist in the activities of the Global Fund projects in Turkmenistan “Ensuring universal access to high-quality diagnosis and treatment of drug-resistant tuberculosis (DR-TB) in Turkmenistan” and the project “Informing managers and primary health care providers about the benefits of the outpatient TB treatment model” which is being implemented in the country in the framework of the regional project TB-REP.



UZBEKISTAN

ORGANIZATION

Non-governmental
organization
Republican
Information –
Education Centre
“INTILISH”



PROJECT

Outpatient Tuberculosis
Treatment

ABOUT THE PROJECT

The goal of the project is to create a favourable informational environment for successful implementation of outpatient treatment of people affected by TB in three regions of the Republic of Uzbekistan — the city of Tashkent and the regions of Syrdarya and Samarkand.

Project activities are focused on development, production and dissemination of TB informational materials based on focus group study results. The information is targeting the general public, people affected by TB and health care professionals. Certain activities were conducted to encourage public opinion to be in favour of implementation of outpatient TB treatment.

Meetings of national working groups were conducted to share experience among stakeholders in the area of TB as well as consultations on the priorities of the advocacy strategy. The implementing partner also actively participated in reforming the legal framework for TB care in the country.

The organization also provides support to people affected by TB at the stage of outpatient treatment by counselling them on adherence to treatment and providing them with food aid.



**Tatyana
Nikitina**

*Director,
Non-governmental
organization Republican
Information – Education
Centre “INTILISH”,
TB-REP Project Coordinator
in Uzbekistan*

” *The TB-REP project in Uzbekistan has created favourable conditions for development of fruitful cooperation in the field of TB between public authorities and civil society. The cooperation is truly effective when partners share the same vision and know how to use each other’s strengths for the benefit of a common cause.* ”

Strengthening collaboration between the state and civil society in Uzbekistan for the effective solution of relevant TB-related issues

One of the most important obstacles to an effective TB response is the absence of cross-sectoral cooperation and an established system of social partnership. In Uzbekistan, the TB-REP project became the platform for building and strengthening such a partnership.

The key tools for establishing partner relations between the grantee of the TB-REP project, Non-Government Non-Commercial Organization “Information and Education Center ‘INTILISH’” (hereafter — NGO INTILISH) and the NTP were a high level of coordination of actions, mutual provision of information and strength-based collaboration.

Implementation of the TB-REP project in 2016-2018 in Uzbekistan has brought significant results. Assessment of the information needs of people affected by TB and their relatives, TB medical personnel and the general population were conducted in three pilot regions. Based on the assessment results, informational and educational materials concerning TB and its outpatient treatment for each of three target groups were developed, approved and published in partnership with the NTP and with the support of WHO and Project HOPE. Also, “Guidelines on Psychological Support and Social Aid for TB Patients in Uzbekistan” was published; the work on psychological support of people affected by TB is going on successfully.

Furthermore, 2018 has been the year of scheduled revision of the main document regulating TB-related operations by medical services in Uzbekistan — Decree of the Ministry of Health of the Republic of Uzbekistan no. 383. Representatives of NGO INTILISH were included in the working group revising this Decree, and civil society for the first time was able to take part in developing a revised version of the document.

As part of the project, NGO INTILISH provided support to the process of revising Decree no. 383 on the Internet. It was their initiative, shared with the NTP and WHO. All interested parties could join the discussion



by using the web site of the organization to provide their comments regarding the future version of the document. Thus, the circle of people who were able to contribute to the legal framework and thus influence the content of planned TB response activities was broadened substantially. All in all, about 100 recommendations have been received and adopted.

In this time of large-scale reform in Uzbekistan aimed, in particular, at increasing the transparency of operations of public bodies, the implementation of innovative tools and methods, as well as development of the role of the civil sector in improving people's access to medical services, partnership between the NTP and NGO INTILISH became a good example of effective collaboration between public and civil sectors in the country.

This collaboration has already been developed further. The Ministry of Health, Ministry of Interior and NGO INTILISH have agreed a trilateral Memorandum of Cooperation, one of objectives of which is to provide TB care to people being released from prison.



Therefore, the three-year sub-project “Outpatient TB treatment” of the TB-REP project has become a platform for forming and strengthening social partnership in Uzbekistan as a reliable basis for sustainable development of the TB response system according to the END TB strategy. Further strengthening of collaboration between the state and the civil sector in Uzbekistan will promote effective resolution of relevant issues concerning the TB response.



UKRAINE



Vitaliy Rudenko

Chair of the Board, Charitable Organization "The Public Movement – Ukrainians Against Tuberculosis Foundation", TB-REP Project Coordinator in Ukraine

”

The TB-REP project has allowed us to take the first steps implementing innovations in cross-agency and cross-sectoral coordination of the TB response at national and regional levels in Ukraine.

”

ORGANIZATION

Charitable Organization
“The Public Movement –
Ukrainians Against
Tuberculosis
Foundation



PROJECT

Creating a favorable
socio-political situation
for transition to an
outpatient form
of treatment for
tuberculosis in Ukraine

ABOUT THE PROJECT

The goal of the project is to raise the level of responsibility of regional authorities with regard to the problem of tuberculosis in the regions of Ukraine, as well as the political commitment of the central authorities to fighting the TB epidemic in Ukraine according to the “Tuberculosis Action Plan for the WHO European Region for 2016-2020” and mobilization of regional communities and the general population of Ukraine to support the people-centered TB treatment model.

Implementation of the project has led to establishing the first organization of people affected by TB in Ukraine, the All-Ukrainian Association of People who Recover from Tuberculosis “Stronger than TB”, and to taking steps to strengthen it and build up its capacity.

In close collaboration with the Association, an awareness raising campaign was held, targeting the general population, to reduce the stigma faced by people affected by TB.

An important component of the project is advocacy at national and regional levels to implement a people-centered TB treatment model. This includes an advocacy campaign to improve the awareness and strengthen the commitment of public authorities and politicians to development and implementation of an effective people-centered TB response model in Ukraine.

To achieve the objectives of the project, the current model of TB care was assessed for its further improvement, based on the detailed TB-REP blueprint.

Strengthening
community impact
on reforming TB care
by establishing
and supporting
the All-Ukrainian
Association of People
who Recover
from Tuberculosis
“Stronger than TB”

In 2014, Ukraine was added to the list of the five countries with the highest MDR-TB burden in the world. Every year in Ukraine, around 23% of the people who need treatment for TB are not detected and thus are not cared for by the national TB services. Also, the country has a low rate of TB treatment success (76% for new and relapse individuals in 2016. 51% for MDR individuals started on second line drugs in 2015. Source: WHO).

Vertically-structured health care, low accessibility to medical services, high levels of stigmatization and discrimination of key groups affected by TB, low awareness of the importance of timely diagnosis and treatment of TB, low socio-economic levels of the population in general, all cause significant obstacles to overcoming the TB epidemic in Ukraine. Also, one of the most substantial negative factors for overcoming the TB epidemic used to be the lack of a consolidated community of people affected by TB able to influence the shape of national and local-level policies in this field.

Despite many years of the TB epidemic in Ukraine, uniting people affected by TB and their involvement in advocacy activities was for the first

time made possible only due to the regional TB-REP project. So, on 28 April 2016, participants of a workshop for people affected by tuberculosis representing 10 regions of Ukraine decided to establish All-Ukrainian Association of People who Recover from Tuberculosis “Stronger than TB”, and adopted a Declaration of Principles and Intent for the Association, defining its main activities and objectives. On 25 December 2016, the Charter of the Association was adopted, and on 10 February 2017 the non-governmental organization “All-Ukrainian Association of People who Recover from Tuberculosis ‘Stronger than TB’” was formally registered with the Ukrainian authorities as a legal entity.

With the support of TB-REP, the “Stronger than TB” Association began organising communities of people affected by TB in Ukraine, initially focusing on Kyiv, Sumy, and Kherson oblasts and the city of Kyiv. In 2018, Mykolaiv oblast joined these regions.

Under the TB-REP project in 2017-2018, workshops and trainings were conducted for members of the organization in three oblasts. Main topics included improving the skills of advocacy to encourage a shift to patient-centered TB care, learning methods for protecting the rights and interests of community members, including those related to overcoming stigma and discrimination, and also the conduct of public monitoring to evaluate the responsiveness of available outpatient services to the needs and expectations of patients at all stages of care.





To promote community activities and ensure effective communication, they created the official web site of the Association (<http://stoptb.in>) and “Stronger than TB” group on Facebook.

The work of the All-Ukrainian Association of People Recovering from Tuberculosis “Stronger than TB” has strengthened civil society’s influence on reforming the TB care system e.g. members of “Stronger than TB” have taken an active part in advocacy for and development of the National Targeted Program to Fight TB for 2018-2021, as well as the Advocacy, Communication and Social Mobilization (ACSM) strategy supporting this Program.

The Association currently includes more than 50 members and keeps growing. Activists of the Association cooperate successfully with regional

authorities on developing regional TB response programs, implementing a social procurement system and increasing the effectiveness of communications with key stakeholders. In addition, the Association’s representatives have also initiated development of comprehensive regional plans for inter-agency and cross-sectoral collaboration against the TB epidemic.

The work of the Association has resulted in strengthening the advocacy capacity of the community of people affected by TB, which in turn has positively influenced processes for reforming the TB response system in the country. This concerns, mainly, transition to a people-centered TB treatment model meant to strengthen the response to and speed of overcoming the TB epidemic.



2018