

12. The Role of NGOs in Engaging Local Communities in Combating Tuberculosis

Introduction

According to the World Health Organization (WHO), tuberculosis (TB) remains a public health problem in Kyrgyzstan. The country is among the 30 countries in the world that have a high burden of multidrug-resistant tuberculosis (MDR-TB) and is one of 18 high TB priority countries in the WHO European Region¹.

In recent years, the Kyrgyz Republic has made significant progress in treating TB². However, reports from the UN Secretary-General, the World Health Organization, TB communities, and civil society indicate that the Covid-19 has set back the progress made in the fight against TB by several years and has also negatively impacted vulnerable groups in society by creating additional barriers to accessing quality healthcare³.

Despite the implementation of the national TB programmes, as well as important programmes and projects supported by international partners, the TB situation in the country remains challenging and requires further improvement.

In 2023, the United Nations General Assembly High-Level Meeting on Tuberculosis was held with the participation of heads of state and government. The meeting resulted in the adoption of the Political Declaration of the High-Level Meeting of the General Assembly on Tuberculosis, which reaffirmed existing commitments under the Sustainable Development Goals (SDGs) and the WHO Strategy

1 www.who.int/europe/ru/news/item/15-06-2017-tb-rep-mission-to-kyrgyzstan-6-8-june-2017/

2 www.24.kg/obschestvo/289427_tuberkulez_nepobedili_nopohvastat_kyrgyzstanu_est_chem

3 www.stoptb.org/file/15587/download

to end TB and announced new commitments. These commitments include:

- Guaranteeing adequate and sustainable funding to ensure universal access to quality TB prevention, diagnosis, and treatment services.
- Ending stigma and all forms of discrimination by eliminating discriminatory laws, policies, and programmes against people with TB, and by protecting and promoting human rights and human dignity.

Several independent studies have been conducted in Kyrgyzstan over the past five years, such as: “Assessment of socio-economic factors, including gender-specific factors, affecting the receipt of health services by TB patients in the Kyrgyz Republic”, for The United States Agency for International Development (USAID) End Tuberculosis Project, 2018.

- “Assessing Factors Influencing the Health Seeking and Treatment Behavior of the Target Population for Tuberculosis”, for USAID’s Cure Tuberculosis Project, 2020.
- Assessment of the real causes of stigma and discrimination towards TB patients by the environment that influences the behaviour of people with TB, Public Fund (PF) “Door”, 2020–2023.
- Assessing the level of stigma and discrimination towards people with TB by healthcare providers, PF “Door”, 2020–2023.

Based on the political declaration supported by the country’s leadership, as well as the analysis of research results, which determined the main strategy to continue working in tuberculosis reducing direction in the country.

Tuberculosis is a socially significant disease associated with many social problems, such as low living standards, unemployment, high levels of internal and external migration, etc.⁴ Often people with TB are representatives of vulnerable groups. Social problems can be a serious barrier to patients’ access to quality health services, as well as to their adherence to treatment. Therefore, not only medical

⁴ www.studfile.net/preview/6056636/page:26/

organisations but also other stakeholders should be involved in TB prevention, detection, and treatment. In this regard, it was decided to strengthen the work in two directions⁵ first is the reduction of all types of stigma and discrimination, as well as other factors that create barriers to the adherence of people with TB to treatment; the second is improving interaction between the National Center for Phthisiology (NCP), regional TB centres, primary healthcare organisations, the Presidential Plenipotentiary Offices, local self-government bodies, civil organisations, local communities, and people with TB in order to provide comprehensive support to TB patients and their families.

Description of the Organisation

The public foundation “Door” was registered in 2009⁶. The main areas of work of the organisation are in the sphere of strategic communications and involvement of stakeholders in the process of implementation of socially significant tasks in society. The foundation has supported such organisations as the President’s Office of the Kyrgyz Republic, the Parliament of the Kyrgyz Republic, the Prosecutor’s Office of the Kyrgyz Republic such as Ministries of Energy, Ministries of Agriculture, Ministries of Education, Ministries of Ecology, Ministries of Economy, etc. As a result, strategic documents defining the main activities in the field of communication with target groups were prepared, information campaigns were conducted, and communities were mobilised to solve local problems.

The foundation has been working on reducing the burden of TB in the Kyrgyz Republic since 2017. In collaboration with USAID’s “End Tuberculosis” project, PF “Door” conducted work to reduce stigma and discrimination against TB patients by their community environment. Activities were conducted in one of the project’s pilot areas⁷. The main focus was on introducing new approaches to change attitudes towards TB patients and their families in the com-

5 www.cbd.minjust.gov.kg/160005/edition/1233942/ru—the

6 www.doormedia.kg

7 www.d408fef9-6491-42d3-9224-c99f414b45a.usrfiles.com/ugd/d408fe_7b92fac630894d0385d7c81a52e02ce8.docx

munities. We identified three main directions of information interaction: (1) work with TB patients' environment in communities; (2) work with religious leaders; and (3) work with educational institutions in the pilot project area. Thus, for the first time an NGO began to fulfil not only a public assistant role, providing various social services (patient care, moral support to the family, etc.), but also to act as a coordinator involving various stakeholders in the implementation of a specific task. This approach created prerequisites for further expansion of TB stakeholders in the regions of Kyrgyz Republic. It ensured a more accurate focus on the problems on the part of various state agencies and local self-government bodies and streamlined the overall reporting on the implementation of state programmes to the Government of the Kyrgyz Republic.

Taking into account the experience gained previously during the strategic planning sessions of the new Local Organizations Network (LON) USAID project "Support for TB Patients", the management of the National Center of Phthisiatry of the Kyrgyz Republic (KR) requested to involve more participants in TB activities (such as various state institutions and local self-government bodies, as well as various associations) to mobilise them to perform specific tasks within their competencies and to develop and test new state-of-the-art methods of TB control.

Based on the goals and objectives of the USAID project "Support for TB Patients", the organisational structure of the foundation was changed.⁸

Thus, in addition to coordinators and involved experts, new staff units were added who work directly on the ground in the communities. These units are each made up of 18 mentors. Their functional responsibilities include advising health workers on reducing stigmatising behaviour towards TB patients, as well as advising health workers on TB alertness (identification of signs, description of the algorithm of actions, etc.). The second group that works in the piloting regions are spokespersons, totalling 18 people. Their functional responsibilities include interaction with the leadership of local self-governance bodies (LSGs) and opinion leaders International Organization for Migration (OIMs) in the communities. In addition,

8 www.doormedia.kg/post/tuberkulez

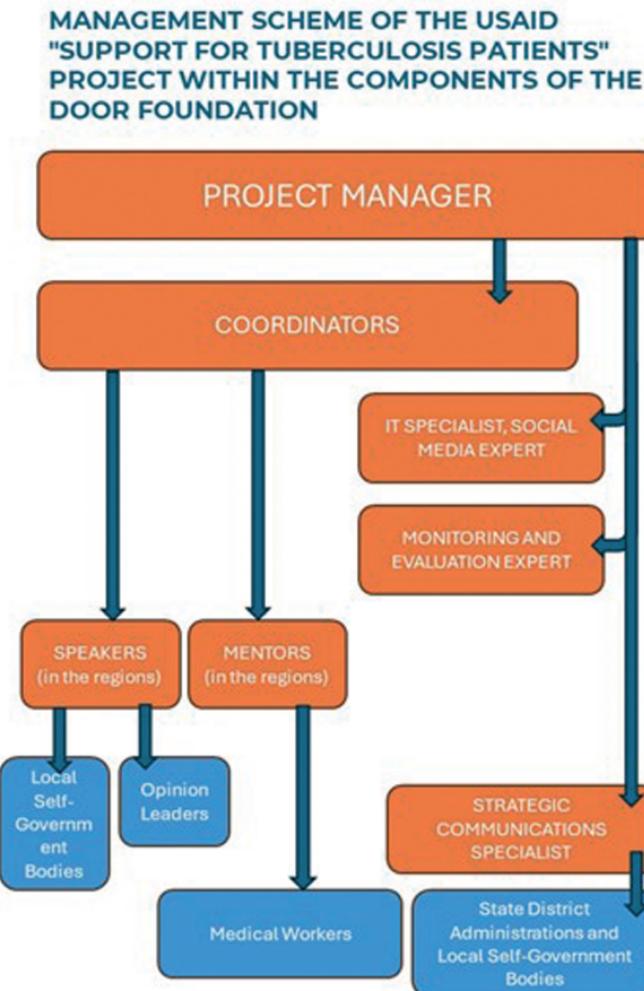


Figure 1: Management scheme of USAID
"Support for TB Patients"

the spokespersons are tasked with conducting systematic information sessions and consultations on the provision of social support from the local budget. In this case, the uniformity of information provision to all stakeholders is ensured by a unified approach to conversations with target audiences, the creation of a single digital databank of relevant and verified media materials, and the availability of digital equipment for the demonstration of all necessary information. The monitoring and evaluation component has been

improved. In this case, the level of information perception by stakeholders is monitored (the sufficiency of information, adequate perception and understanding, and the quality of its interpretation are assessed).

An important stage of the foundation's work was a clear system of two-level planning: strategic planning for the year and operational planning on a monthly basis. At the end of each month, indicators are checked against the stated plans and quarterly monitoring visits are made to double-check the indicators. This in turn ensures clear control over the whole process and improves the quality of planning management and emergency adjustment of plans.

Thus, the importance of the foundation's work in the overall TB control activities in the Kyrgyz Republic can be defined as a demonstration of successful establishment of systemic support to local governments, state administrations of TB patients, and their families. The foundation has also contributed to reducing stigma and self-stigma in society.

The main difficulties that were identified during the first studies (described in the Introduction) were the lack of coordination and consequently haphazard efforts of all parties involved in TB activities.

At the level of Ayil Okmotu⁹ this involved: (1) a lack of systematic provision of social support for TB patients and their families; (2) a lack of skills in handling applications and appeals for social support; (3) a lack of skills in forming a socially oriented budget within Ayil Okmotu's authority, as well as reporting mechanisms to the fiscal authorities and the Audit Chamber of the Kyrgyz Republic; (4) weak legal literacy in terms of authority and opportunities to participate in TB activities; (5) a lack of practice in discussing the formation of socially oriented budgets; (5) a lack of information about the socially oriented budget; and (6) a lack of information about the socially oriented budget.

At the level of healthcare facilities this involved: (1) insufficient coordination with state district administrations and local self-gov-

⁹ (Village government)—executive-administrative body under ail (village) or settlement kenesh, which manages the affairs of life support and the vital activities of the local community.

ernance bodies (i.e. a lack of general annual planning with descriptions of the specific actions of responsible persons and indicators for verification, as well as interaction on prevention, detection, and follow-up of TB patients on outpatient treatment); (2) an outdated structure of training/education of patients to transition to outpatient treatment; (3) a lack of psychological support services for patients facing difficult life situations and increased anxiety; (4) the presence of stigmatising behaviour on the part of medical staff towards TB patients; (5) poor vigilance of medical staff/non-specialists¹⁰ upon the initial reception of patients with TB symptoms.

At the level of State District Administrations this involved: (1) TB activities not being prioritised; (2) TB activities that were often haphazard, fragmented, and limited to TB Day events on 24th March; (3) reporting on TB activities that was not systematic and did not assess stakeholder engagement to address TB challenges.

At the community level this involved: (1) the dissemination of myths about TB (these are still quite popular in communities, although public awareness of TB prevention and treatment is increasing); (2) poor legal literacy in terms of providing support to TB patients and their families at the state and local government levels; (3) disorientation in finding understandable and verified information related to TB.

Based on the identified problems, a strategy was developed to involve all stakeholders in TB activities. Specific actions were taken to unite efforts in different areas. Various innovative products were also created to automate processes related to prevention, increasing adherence to treatment, and bureaucratic issues.

The first approach involves incorporating TB-related activities into local plans and strategies related to social care and healthcare. The advantages of this approach include having activities approved by management and maintaining a common reporting schedule. However, there are also disadvantages, such as the risk of formalizing the implementation process too much; assigning random staff without the necessary skills to be responsible for implementation; and the potential omission of important points due to an overloaded common list of activities.

¹⁰ Non-specialists in medicine are only concerned with examining and treating patients in a specific area.

The second approach involves creating and adopting unique strategies at the oblast level, which provide broad coverage of the issue through a customized list of tasks tailored to the specific characteristics and needs of the region. The advantages of this approach include securing high-level support, developing an exhaustive list of tasks in action plans, the potential for integrating various services and agencies at the oblast level, and the inclusion of strategy implementation results in the PR plan of the oblast leadership. The disadvantages include the lengthy timeframe required for coordination and lobbying for adoption.

All of the actors described above, who in one way or another are involved in TB activities, exist in a general system of public administration, which changes depending on the political conjuncture. The changes of power in the highest political circles changed this system to realise certain political objectives. The current political course is aimed at strengthening the vertical of power at all levels. Below is a diagram illustrating the state of affairs in which NGO activities to reduce the burden of TB in the Kyrgyz Republic are being implemented.

All partners noted in the scheme are guided by the current legislation of the Kyrgyz Republic. The new version of the Law of the Kyrgyz Republic “On Public Health” provides for the unification of five existing laws of the Kyrgyz Republic, namely “On Public Health”¹¹, “On Immunoprophylaxis of Infectious Diseases”¹², “On Protection of the Population from Tuberculosis”¹³, “On HIV/AIDS in the Kyrgyz Republic”¹⁴, and “On Prevention of Iodine Deficiency Diseases”¹⁵.

“The new law aims to improve the norms in accordance with modern public health challenges and requirements, and also takes into account international law enforcement practices. Among the main objectives of the law are prioritization of prevention, strengthening cooperation between public health actors, elimination of duplicative and contradictory norms, as well as increasing the use of

11 www.cbd.minjust.gov.kg/4-5301/edition/3727/ru

12 www.cbd.minjust.gov.kg/463/edition/816710/ru

13 www.cbd.minjust.gov.kg/73/edition/942342/ru

14 www.cbd.minjust.gov.kg/1747/edition/1091612/ru

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DEVELOPMENT OF REGIONAL TUBERCULOSIS STRATEGIES WITH AN ACTION PLAN

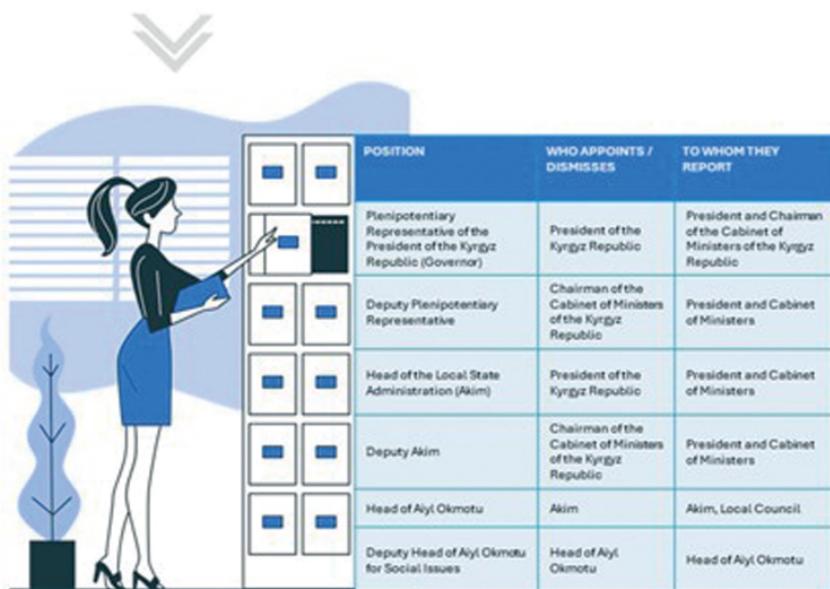
NGO



EXAMPLE: "Naryn Region Without Tuberculosis" Strategy

Figure 2: Development of Regional TB Strategies with an Action Plan

STATE GOVERNANCE SYSTEM IN THE REGIONS OF THE KYRGYZ REPUBLIC



SYSTEM OF INTERACTION BETWEEN LOCAL COUNCIL DEPUTIES AND THE HEAD OF AIYL OKMOTU

Responsibilities of Local Council Deputies:

1. Approval of the local budget and the report on its implementation, as well as hearing information on the progress of budget execution and the use of extra-budgetary funds.
2. Approval of programs for socio-economic development of the territory and social protection of the population, and hearing the report on the implementation of the program.
3. Hearing the report of the head of the local self-government executive body on the activities of the local self-government executive body.
4. Election of the Chairman of the Kenesh and their deputy, dismissal from office, and annulment of the Chairman's decisions that contradict the law.
5. Control over the implementation of their decisions.
6. Expression of no confidence in the head of the local self-government executive body.
7. Proposal to consider the issue of compliance with the position of the head of the local self-government executive body due to non-implementation of the budget, socio-economic development programs of the territory, social protection of the population, and other issues within their competence.

Figure 3: State Governance system in the Regions of KR

digital technologies to improve accessibility and efficiency of public health services for the population.¹⁶

In providing support to TB patients and their families, state administrations and local self-government bodies are primarily guided by the articles of the Constitution of the Kyrgyz Republic, the Budget Code, the Law “On Local State Administration and Local Self-Government Bodies”¹⁷, the Law “On the Basics of Social Services in the Kyrgyz Republic”¹⁸, the Law “On State Social Order”¹⁹, the Law “On the Rights and Guarantees of Persons with Disabilities”, the Law “On Protection of the Population from Tuberculosis”²⁰, the Law “On Elderly Citizens of the Kyrgyz Republic”²¹, and the Law “On Health Protection of Citizens in the Kyrgyz Republic”²².

Involvement of Local Self-Government

Referring to the Law of the Kyrgyz Republic “On Public Health”²³—Powers of local state administrations and local self-governments in the field of health protection of citizens, Paragraph 18—Provision of social support to persons who have fallen ill and recovered from TB, a lobbying strategy was developed to increase social support for TB patients and their families. According to PF “Door” Theory of Change, “If social support is provided at a systemic level and without barriers, stigma towards TB patients will be reduced and patients will become more committed to treatment”, it was necessary to increase the number of local governments that openly support TB patients and include this in their budgets.

For this purpose, with the support of regional and district state administrations, based on the current legislation and regional

16 www.kg24.news/obschestvo/kak-novyy-zakon-o-zdravoohranenii-otrazitsya-na-grazhdanah-kyrgyzstana.html

17 www.cbd.minjust.gov.kg/112448/edition/1200696/ru

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22 www.cbd.minjust.gov.kg/4-5260/edition/1939/ru

23 <https://cbd.minjust.gov.kg/4-5301/edition/3727/ru> Article 9

strategies for TB elimination, a schedule of a series of trainings for the leadership of local self-governments was drawn up. Participants of the trainings are chairpersons of territorial associations, accountants, social workers, and deputies of local Kenesh.²⁴ Immediately prior to the events, project speakers visited each participant and conducted an information session on “the role of the community in TB elimination”. Thus, the audience was maximally prepared and involved in the process.

The trainings included topics on increasing expenditure items for social expenditures, modifications of expenditure items for emergency social support, and reporting on expenditure items to the fiscal authorities and the Chamber of Accounts of the Kyrgyz Republic, as well as an algorithm for introducing issues on social support for TB patients and their families into budget discussions. During the trainings, participants drafted programme budgets, which were then presented at the general meeting. At the same time, TB patients from socially vulnerable groups were trained on how to apply for financial assistance. A single, unified application format was developed and agreed upon with competent lawyers and law enforcement agencies. A list of documents to be attached to the application was compiled. The general lobbying scheme is presented below.

As a result of lobbying for budget changes in local communities: (1) more than 90 local government administrations increased their budgets; (2) the total cumulative change came to more than 40,000 euros; (3) more than 50 local governments introduced a new expenditure item in the budget “for TB activities” (4) more than 300 patients and their families were provided with social support both in cash and in kind; (5) twelve local government administrations committed themselves to employing patients and their families²⁵; (6) a uniform approach to the design and procedure for disbursement of funds for patient TB support was created, as well as a uniform approach to reporting on funds used; (7) a mechanism for reporting

²⁴ The Kenesh is a representative body of local self-government elected by the citizens of Kyrgyzstan for a five-year term.

²⁵ www.tbc.kg/td

METHODOLOGY FOR LOBBYING BUDGET CHANGES WITH A SOCIAL ORIENTATION



CONDUCTING TRAININGS ON CREATING A SOCIALLY ORIENTED BUDGET FOR DECISION-MAKERS:

1. Local Kenesh deputies
2. Heads of Alyl Okmotu
3. Accountants
4. Social workers

CONDUCTING PRESENTATIONS OF BUDGET DRAFTS:

- Consultation on budget changes with a focus on social orientation

WORK WITH EMERGENCY MEDICAL SERVICE (EMS) AGENCIES TO IMPROVE AWARENESS OF TB LEGISLATIVE FRAMEWORK



- Law on the Protection of the Population from Tuberculosis
- Law on Local State Administration and Local Self-Government Bodies
- In the near future, the new edition of the Law of the Kyrgyz Republic "On Public Health"



CONSULTING PEOPLE WITH TB ON RECEIVING FINANCIAL ASSISTANCE FROM LOCAL SELF-GOVERNMENT AUTHORITIES

- Specialists from the "Door" Foundation
- Speakers of the "Support for Tuberculosis Patients" project



Unified application template for pilot regions

MONITORING BUDGET CHANGES WITH A FOCUS ON SOCIAL ORIENTATION

- Requesting reports from Alyl Okmotu that reflect the amount of funds allocated for social items and the reserve fund.
- Analysis of the reports and data from the National Statistical Committee on budgets by an engaged expert. Presentation of the analysis results to the regional leadership by specialists from the "Door" Foundation.

SCHEME FOR USING FINANCIAL RESOURCES FOR SOCIAL SUPPORT OF TB PATIENTS AT THE COMMUNITY LEVEL

- Identification of Needs: A phthisiatrist compiles a list of patients in need and certifies the diagnosis with a medical certificate.
- Application Assistance: A social worker and a project speaker assist the patient in submitting an application to the Alyl Okmotu. The application is written on an official form and attached with a certificate from the phthisiatrist.
- Housing Inspection: A commission inspects the housing conditions of the patient.
- Application Review and Approval: The application is reviewed and approved.
- Payment to the Needy Patient: The patient in need receives the payment.
- Receipt Confirmation: After payment, a receipt is obtained from the patients confirming that the assistance was indeed provided.
- Annual Local Self-Government Budget Report: An annual report on the budget is prepared by the local self-government.

Figure 4: Methodology for Lobbying Budget Changes with a Social Orientation

to the district and regional administration on TB activity indicators was introduced²⁶.

Integration and Strengthening of the Role of Health Facilities in the Overall TB System

Based on the findings of the baseline study regarding stigmatising behaviour on the part of health workers towards TB patients, it was decided to train medical staff of Primary Healthcare (PHC) services on interpersonal communication with TB patients in order to reduce stigma towards people with TB. For this purpose, a special course on “Interpersonal Communication” was developed jointly with the Kyrgyz State Medical Institute for Retraining and Professional Development. Together with the oblast health coordinators, a list of health workers and a schedule of seminars was compiled. To increase the status of the training, the Institute provided the training participants with credit hours.²⁷ Specially trained mentors (mentors are part of the organisational structure of the Foundation) the health workers’ level of perception of the training material and their ability to use the acquired skills at patient appointments. During mentoring visits, according to a pre-agreed procedure, the mentor records the presence or absence of elements of stigmatising behaviour on a checklist in the presence of the patient and health-care provider. The data is then processed, and recommendations are made on how to improve performance. Each mentor is required to make such visits to a minimum of six health workers per month in different geographic locations. Reporting is presented to the regional health coordinators. This approach has helped to develop consistent patterns of behaviour among health workers that eliminate stigmatising behaviours towards TB patients.

Responding to the request of the Ministry of Health of the Kyrgyz Republic to improve the detection rate, work with health workers was strengthened to increase their alertness upon initial reception of patients with TB symptoms. For this purpose, a lecture explain-

26 www.d408fef9-6491-42d3-9224-ec99f414b45a.usrfiles.com/ugd/d408fe_fb62bb1ba9c64271a19513fc56aaeb65.docx

27 The cumulative system of “credit hours” allows the labour intensity of continuing education to be measured, summarizes “credit hours” over a five-year period, and gives the specialist the opportunity to be certified for admission to work and/or assignment of a qualification category.

ing the sequence of actions to be taken when a patient shows TB symptoms was included in the objectives of the mentoring visits. The layout of the talk was developed based on approved clinical protocols. As a result, more than two hundred people were sent for additional examination by health workers/non-specialists and one in ten was found to have TB in one form or another. For the convenience of users, all information regarding the orders of the Ministry of Health of the Kyrgyz Republic and the whole algorithm of actions has been digitised and placed in one location, namely the “Unified Communication Digital Platform TVS”²⁸.

Violation of doctor’s prescriptions by people with TB is one of the most serious and intractable problems that lead to a decrease in the effectiveness of treatment of sensitive TB, the formation of drug resistance, and the spread of infection in the community. Despite all measures taken, the problem of early drug discontinuation in outpatient treatment remains unsolved. In this regard, it is crucial to prepare TB patients on inpatient treatment for transition to outpatient treatment. The training programme for people with TB entitled “Zheenil dem al” was developed within the framework of the project by the Deputy Director of the TB Centre. It includes 16 sessions for patients receiving inpatient treatment. In order to unify the training material, all lessons were designed as ready-made media blocks and placed in one platform²⁹: In this way, the lesson can be viewed from any digital media. The main objectives of the training programme “Jehneil dem al” are as follows: (1) to help the person with TB to take on the responsibility for maintaining his/her health by following a controlled treatment regimen; (2) to provide patients with the necessary knowledge about TB, modern methods of treatment, diagnosis, and prevention of TB; (3) to provide patients with detailed training on what a healthy lifestyle looks like, on work and rest regimes, and on nutrition; (4) to facilitate the adaptation of TB patients to the outpatient phase of treatment to increase their motivation for successful completion of treatment; (5) to reduce the workload of physicians by giving them the opportunity to work with well-informed patients; (6) to familiarise patients with the mechanism of interacting with local authorities to receive social support.

28 www.tbc.kg/pmsp

29 www.tbc.kg/sp

The training programme “Zhenil dem al” was presented by the Deputy Director of the TB Centre at the ceremonial meeting of the Scientific Council of the NCF dedicated to World TB Day. Members of the Academic Council noted the importance of preparing TB patients for transition to outpatient treatment. A recommendation was made by the Academic Council of the NCP to implement an updated form of patient education. At the request of the management, the training programme was implemented in pilot hospitals, namely Naryn and Jalal-Abad regional TB control centres. The responsible staff working at the hospitals received online training on the methodology of teaching the training programme “Zhenil dem al”. The public fund “Door” trained 18 medical staff of Naryn and Jalal-Abad TB centres, including the skills of using the Unified Digital Communication Platform to improve patient information. Training of staff at the pilot oblast TB control centres facilitates the continuity and interchangeability of trainers of the “Zhenil dem al”. Test training of patients in the pilot hospitals was conducted, which helped to fine-tune the teaching methodology. In the Naryn and Jalal-Abad Center for Tuberculosis Control (CTC), patients were tested for adherence to four indicators, namely drug therapy, medical support, lifestyle modification, and treatment, as well as having their anxiety levels evaluated, before the start of the “Zhenil dem al” training programme and after the completion of all sessions. The test results showed that after the training, adherence to drug therapy, medical support, lifestyle modification, and treatment increased in 79.5 % of patients. Meanwhile, anxiety decreased in 85.5 % of patients who received the training. Patients were also tested weekly to assess the level of assimilation of information learned during the classes. The results of the weekly assessment of learning showed that more than 75.5 % of the patients learned the information included in the training programme perfectly (i.e. they answered 90 % or more of the questions correctly)³⁰.

Participants of the Training program that was defined as “Zhenil dem al” School undergo several control tests, such as the anxiety level test³¹. This test determines situational and personality anxi-

³⁰ www.d408fef9-6491-42d3-9224-ec99f414b45a.usrfiles.com/ugd/d408fe_98939b8e1dc04702b9401c3ee72dc844.docx

³¹ www.tbc.kg/post/тест-тревожность

ety. An automatic response-indicator indicates to the trainer in the “Zhenil dem al” School the baseline at the initial level. After completing half of the course, the “student” takes the test again and the system responds to changes in anxiety levels. For the trainer, this is an indicator as to whether to conduct additional counselling, apply other approaches with the patient, or continue at the same pace and with the same methodology. The second test that the participants of the “Zhenil dem al” School undergo is a test to determine the degree of readiness to change their lives in accordance changes in society. The “Commitment to Treatment” test³² is also taken twice during the whole course by the participants of the “School”. The trainer, based on the results of the analysis of the automatic system, records the degree of the patient’s commitment to comply with the conditions of treatment and the recommendations of the attending physician. If at the end of the “Patient School”, the participant’s adherence is low, a note is made in the accompanying documents for the attending physician and nurse to ensure they pay attention to the risk that this person may withdraw from treatment. The nurse and the social worker then work together to develop a communication plan for the patient and record any deviations from treatment. In this way, the Patient School also acts as an important element of local government involvement in TB control. Pilot “Patient Schools” have been approved by the heads of TB inpatient facilities. Patient School trainers have been given new functional responsibilities and a system of reporting, and an evaluation of their performance has been developed. The initiative has been reported to the heads of oblasts (Jalal-Abad and Naryn oblasts). The diagram below illustrates the mechanism of interaction between health workers and representatives of local government.

The PF DOOR actively cooperates with district administrations and advises them on the implementation of initiatives aimed at TB prevention and treatment. One such initiative is to introduce information about the BCG vaccination—and the benefits of it—in the form of interactive talks with pregnant women and young women. The structure of the talk is based on key moments in the plot of the Kyrgyz national game of alchiki³³. Scenario presented in the inter-

32 www.tbc.kg/post/testpr

33 www.youtube.com/watch?v=o7p5VJj1dxc

PATIENT SCHOOL

an element of involving local authorities in the process of combating tuberculosis



Action mechanism for detecting low patient adherence:

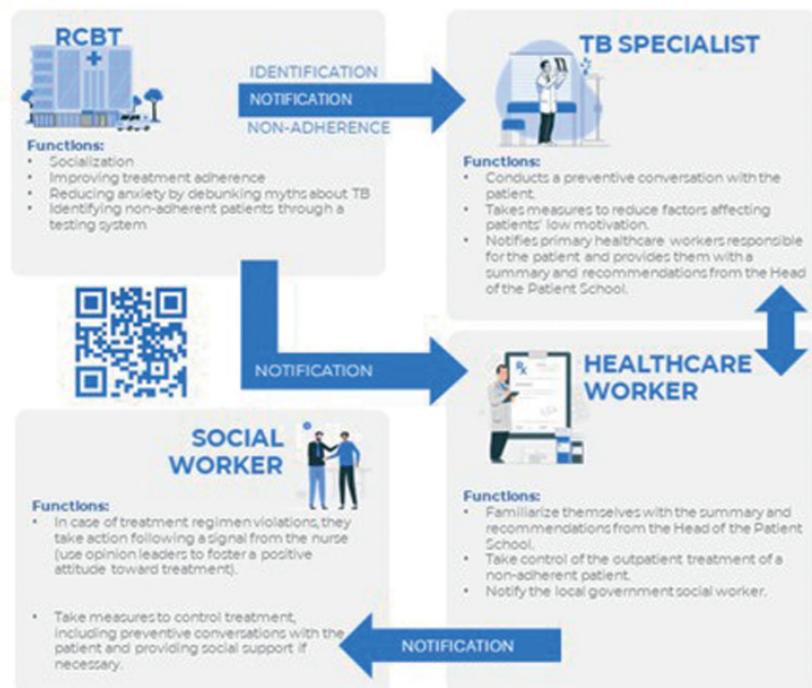


Figure 5: Patient School

active talk, for each win a woman has to answer a question and only then can she collect the prize. The need for these interviews arose after the Project received requests for support from health workers and heads of district administrations who were concerned about the increasing number of cases of parents refusing BCG vaccination for newborns. The main reason for refusals is the dissemination of misleading information about vaccination. Using elements of the national game of alchiki, as well as video materials from the Project, speakers provide participants with basic information about the BCG vaccine and answer questions about the safety of it. 95 % of the participants of these events noted that they understand the importance of TB vaccination for new-borns and do not intend to refuse vaccination in the maternity hospital. The interactive talk was implemented in the “School of Mothers” (a training course for pregnant women run by medical institutions in all municipality of the Zhumgal district of Naryn province. This initiative was announced by the deputy governor on social issues. Previously, “School of Mothers” was held only at the district level. According to the deputy akim, better informing pregnant women about BCG will help to improve vaccination rates of newborns and, as a consequence, TB prevention in children.

As a result of the Project activities, it became clear that it was necessary to provide TB patients with psychological support using information and communication technologies (ICT). This is due to the lack of qualified psychological support in all regions of the Kyrgyz Republic. The only solution to overcome this situation is to support TB patients to cope with psychological difficulties during long-term treatment using artificial intelligence that can carry out some of the functions of a psychologist. For this purpose, a self-learning digital program customised for TB patient interaction was created. The virtual psychologist was based on several principles: (1) convincing patients of the importance of taking a course of medication to cure TB; (2) the program expresses understanding and empathy, offering moral support and reassurance; (3) the program motivates patients to continue and complete treatment, emphasising positive aspects and the ultimate goal of full recovery; (4) the program provides relevant and understandable information about TB, its treatment, and the importance of following the doctor's recommendations. (The instructions and basic messages of the pro-

gram are taken from the “Knowledge Base” section of the TBC.kg website).

To realise the set objectives, experts in the field of psychology conducted several focus groups to identify the main needs of people with TB who had started treatment and need psychological support. As a result, an algorithm of interaction and a description of the positioning of the virtual psychologist were determined. Interaction consists of the following blocks: (1) Introduction: the system starts the conversation with a warm greeting and offer of help; (2) Reaction to doubts: in case the patient expresses doubts about the need to continue treatment, the system provides motivating arguments and support; (3) Tips for overcoming difficulties: the system offers practical advice and methods for solving possible difficulties in the process of treatment; (4) Fatigue from the topic: at the user's request, the system instantly switches to other topics, rather than aggressively imposing the topic of TB; (5) Ending the conversation: the system ends the communication by expressing support and reminding the patient about the availability of help at any time. When it comes to the positioning of the system, according to focus group participants, the virtual psychologist should be able to keep doctor–patient confidentiality and be tactful. The model of interaction for all stakeholders with the digital system is presented below.

The virtual psychologist was developed using advanced artificial intelligence and machine learning technologies, which allows it to not only provide qualified psychological support, but also to adapt to the individual needs of each user. An initial survey of respondents began in January 2024 to understand what beneficiaries want the virtual assistant to be like. 88 patients and 25 nurses from the four pilot areas of the project participated. 72 % of patients responded that support on the road to recovery was very important to them. 78 % of respondents said that getting advice and guidance was the most important thing for them in the chatbot. 62.5 % of respondents said that it is important for them that the chatbot adapts to their requirements and that motivation for recovery is important for them. Most noted that they expected the chatbot to be supportive and envisioned the chatbot as a middle-aged, Asian male, ready to answer any questions. All respondents admitted that they would like to be able to receive reliable information at any time based on their

VIRTUAL PSYCHOLOGIST "DR. AZAMAT" AS THE FOUNDATION FOR DIGITAL INTERACTION AMONG ALL STAKEHOLDERS IN REDUCING THE BURDEN OF TB

TASKS

- Increasing motivation for treatment.
- Answering any questions on the topic of TB.
- Using verified data and recommendations from scientific literature in responses.
- Reminding of the importance of following medical recommendations.

- ▶ Accessibility
- ▶ 24/7 TB consultation
- ▶ Self-learning



ADVANTAGES

USE IN MEDICAL ORGANIZATIONS



- 1 Assisting the patient and their relatives in accepting the diagnosis.
- 2 Preparing the patient for treatment
- 3 Motivating to complete treatment.

USE BY LOCAL SELF-GOVERNMENT AUTHORITIES



- 1 Recommendations for local self-government authorities on what specific assistance to provide to patients
- 2 Consultation of staff on TB-related topics and eco-friendly communication with people with TB

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Figure 6: Virtual Psychologist

queries. Many interviewed patients lack psychological support and are glad that such an assistant can be available.

Then the beneficiaries (88 patients and 25 nurses) were invited to use the demo version of the chatbot created on the basis of the results of the first questionnaire. After using the virtual assistant, recommendations and wishes were received from volunteers, which were taken into account when finalising the chatbot. After the changes were made, 85 people from the four pilot areas (35 nurses and 50 TB patients and ex-TB patients) actively used the chatbot for five weeks. Volunteers were from different social backgrounds, living in different geographical locations, and of different genders and ages. At the end of this testing phase, 75 % of respondents said that the chatbot answered all their questions clearly and understandably. 62 % responded that what they liked most about the chatbot was that it provided advice and guidance. 93 % of people said that the chatbot provided them with a sufficient level of psychological support. 65 % of volunteers said that the chatbot helped in increasing their adherence to treatment. 86 % of respondents said they would continue to use the chatbot regularly. More than half said that they trusted the electronic system than they trusted their relatives. The experiment was supervised by qualified psychologists who recorded the moral and psychological state of the patients. At the end, an evaluation report was prepared with recommendations for the use of the virtual psychologist system for all long-term patients.

The final conclusion of the experts noted that “the peculiarity of this product is its ability to support patients and their loved ones in difficult moments, providing not only specialized advice, but also psychological support. The virtual psychologist is able to guide patients who are at risk of interrupting treatment, thus ensuring a higher probability of complete cure”.

Regional and District State Administrations' Own Initiatives

The impetus for launching their own initiatives at the level of state regional and district administrations was the implementation of the strategy "Cultivating Value". The strategy itself envisages a step-by-step implementation of various initiatives at different levels. The first level is the implementation of small-scale initiatives at the community level. For example, providing ten families of TB patients with fuel for the winter. The positive impact of this action is included in the information folder for reporting to the district government administration. It is then proposed to scale up several initiatives to the district level. Together with the management of the District State Administration, an annual action plan for TB activities is developed, responsible staff are appointed, and deadlines are set.

The results of such activities were: the introduction of new approaches in the educational system (an open lesson on "TB prevention" was developed and implemented in schools on the recommendation of the Ministry of Education and Science of the Kyrgyz Republic); lectures on the importance of BCG vaccination were developed and implemented at the level of antenatal clinics (in some districts, the percentage of vaccinated children reached 97%–98%); sputum collection points were built; collection points for poor TB patients were opened; expensive medical equipment was purchased (digital X-ray and traditional X-ray equipment).

These initiatives are reported to the regional leadership, where even more ambitious initiatives are already underway. One successful example is the mass TB screening of children at risk. At the initiative of the Presidential Plenipotentiary Mission in Naryn oblast, mass TB screening of children was conducted. This initiative was the result of coordination among stakeholders involved in TB control in the oblast. As a result of the coronavirus pandemic, the detection rate of tuberculosis has decreased worldwide, including in Kyrgyzstan. Experts predict that this could lead to a sharp increase in the number of patients in the coming years. Health workers and local authorities in Naryn Oblast have joined forces to detect new cases of TB among children and start treatment as early as possible.

Health workers provided the necessary amount of tuberculin for screening. Lists of children from the target groups were compiled. Local authorities organised the arrival of children to the district medical organisations. Parents were also sensitised about the safety of the Mantoux test and the purpose of screening. Project staff in Naryn oblast also took an active part in outreach activities.

The survey covered contact children, children from socially vulnerable families, and children of migrants. A total of 3,825 children aged four to twelve took part. The Mantoux test was positive in 174 children. After additional X-ray examinations, tuberculosis was diagnosed in seven children. These children were referred to the National Center for Phthisiology in Bishkek. Nine children were prescribed prophylactic chemotherapy based on the screening results. The Mission expressed readiness to provide additional support for the treatment of children diagnosed with TB.

According to the Naryn TB Center Director, the results achieved during the screening are very good, as in a short period of time it was possible to identify not only the children who were sick, but also the persons who were in contact with them. The implementation of the screening was also highly appreciated by the NTF. According to experts' estimates, 17 cases of tuberculosis among children were registered in Naryn oblast in 2019. In 2020, this indicator decreased. Thanks to the mass screening conducted, it was possible to improve the detection of new cases of TB among children for 2021 and return to pre-COVID indicators. This analysis by NTF specialists was sent to the Ministry of Health.

Based on the results of the successful mass screening of children for tuberculosis, USAID's project "Support for Tuberculosis Patients" was recognised with a letter of appreciation from Sabyrkul Ashimbayev, the Plenipotentiary Representative of the President in Naryn Oblast.

As a result, the staff of regional administrations gained the skill of organising and conducting large-scale events, which were carried out at the expense of their own human resources and their own budget.

Informing the Public

The main source of information is the Unified Communication Digital Platform (UCDP) www.tbc.kg. All relevant and verified information on tuberculosis is placed on the platform. The [tbc.kg](http://www.tbc.kg) platform is integrated into the following resources of the Ministry of Health of the Kyrgyz Republic: the official website of the Ministry of Health of the Kyrgyz Republic, med.kg; and the e-Health Portal of the Kyrgyz Republic, i.med.kg.

The Platform provides users with the following features: (1) language selection; (2) by pointing the cursor on the map, it is possible to get up-to-date information on active TB cases in a particular area; (3) the possibility to subscribe to news. In the “Important to Know” section (which helps to reduce rumours), information is provided on the following topics: (1) basic information; (2) prevention; (3) treatment; (4) myths about TB; (5) stigma; (6) free medical services. There is also a news section, the purpose of which is to provide first-hand information on TB and to facilitate coordination among partners. The content of the news section is based on the format of Wikipedia. A system of likes and comments is implemented. There is also a section entitled “Guide”. These pages are realised with the help of Google Docs, so for the user, any geographical area is already ready to be analysed based on existing data. This section provides data on: (1) medical institutions; (2) laboratories; (3) feldsher-obstetric stations; (4) NGOs working in the field of TB; (5) state institutions ready to support TB patients and their families within the framework of the current legislation. Information on the “Employment” and “Patient School” sections is described above. Social networks are represented by pages about health in the regions on Kyrgyz Republic, “*kalktyn salamattygygi*”. In order to increase the importance of information exchange, these pages regularly collect comments from local government officials. Topics for discussion include discussion of seasonal diseases and the prevention of tuberculosis and other infectious diseases in the section “Answers from the National Center of Phthisiatry”³⁴. Extended reports and films are periodically produced on the topics of economic benefits of social

³⁴ www.tbc.kg/post/вопросы-к-нцф-каким-бывает-кашель-при-туберкулезе-легких

support for TB patients, combating stigma, and community-based social support³⁵.

Direct Communication with Target Audiences to Change the Attitudes/Behaviour of People in Communities

To address this issue, the mechanism of direct communication was applied for the first time. This method involved identifying opinion leaders within communities, documenting their stance on tuberculosis patients, preparing specialized informational materials, and subsequently organizing and conducting informational sessions with these opinion leaders. At the end of the information session, the level of information perception and changes in attitudes towards TB patients were assessed. This approach immediately found support from the leadership of Aiyil okmotu (the local government administration—AO). Representatives of the administrations could publicly attend the communication activities to answer questions from participants. When planning direct communication activities, consultations were held in advance for heads of local administrations on TB prevention, treatment, and support. This made it possible to strengthen the outreach component and support the structural unit of the Ministry of Health of the Kyrgyz Republic.

Youth Work

Development of a modular video on TB (focusing on stigma and discrimination) with the participation of opinion leaders (TB ambassadors) and its subsequent broadcast on local television and social media. Together with the K. Bayalinov Republican Library for Children and Youth, a modular video titled “Messages for Children with TB” was produced³⁶. The children from Bishkek recorded video messages so that the young patients who are currently under-

³⁵ <https://photos.onedrive.com/share/A15A944BD2494FE!15456?cid=A15A944BD2494FE&resId=A15A944BD2494FE!15456&authkey=AFNuHHr7sDqk480&ithint=video>

³⁶ www.facebook.com/watch/?v=196523272243124&ref=sharing

going treatment in the hospital would believe in their recovery and realise that there are people who are ready to support them. In order to make the leisure time of the children in hospital more exciting, children from Bishkek, gave them gifts, along with good wishes³⁷. After the modular video was published, messages from the children from Bishkek were collected and delivered to the children's ward of the Jalal-Abad Regional TB Center. Together with warm wishes, the young patients received soft toys, chess sets, drawing sets, books, balloons, and fruit. The gifts were presented by the director of the National Center for Phthisiology. The story about presenting gifts to the children in hospital was aired on Jalal-Abad TV³⁸.

A comic book about stigma in school has been developed for teenagers. The main idea is to show how difficult it can be for a teenager to live without the support of others.

Holding Press Conferences

Periodically in the oblasts of the Kyrgyz Republic, the PF Door organises field press conferences. The purpose of the media events is to familiarise the media with the results of the work of the project on changing the behaviour of local communities in relation to people affected by TB. The main speakers are: (1) project speakers; (2) social workers of aiyl okmotu; (3) health workers; (4) local residents; (5) the management of aiyl okmotu, etc.

Conclusion

It should be noted that the work of NGOs takes place in conditions of political turbulence in the country. Furthermore, there is the issue of the introduction of new laws. According to the OSCE Statement of 7th February 2024, new laws may have an extremely negative impact on civil society, human rights defenders, and the media in Kyrgyzstan.

37 www.facebook.com/DoorMediaKg/videos/692180986051335/

38 www.youtube.com/watch?v=snhfZrTNCxY

The main successes of the Foundation's activities include the fact that the topic of TB has become a priority in the regions of the country, in addition to important social problems being solved in the society. This was confirmed by the approval of regional anti-TB strategies by the regional leadership. Inclusion in general consolidated reports should cover not only the number of TB patients and registered patients, but also the amount of social assistance provided. Additionally, these reports should reflect participation in campaigns and support for regional initiatives, such as mass screening of children at risk for TB.

At the municipality level, there should be the development of annual TB action plans, participation in joint activities with health workers to identify individuals with TB, and follow-up with TB patients undergoing outpatient treatment. Municipalities should also be involved in discussions of social issues with the district phthisiatrist, including hearing their reports and proposals for collaboration. Additionally, they should plan for the procurement of medical equipment and ensure the inclusion of TB patients in the State Program "State Social Contract," funded from the state budget.

The municipality administration should include specific obligations in their work plans to support the employment of TB patients and provide comprehensive social support. This includes assistance with food, provision of fuel during the autumn-winter period, and help with employment. Additionally, support may involve providing construction materials for building homes, offering agricultural land leases on preferential terms for crop growing, and organizing social activities.

Notably, the participation of TB patients in festive events, something rarely done before, is an important social step. These community gatherings, often involving a hundred or more people (neighbors, acquaintances, relatives), allow for social cohesion, as joint participation in the celebration shows community support.

A gender-sensitive approach was also considered when engaging target audiences. The research conducted by PF Door highlighted a significant stigma toward women with TB. Women with TB often experience negative attitudes from their spouses and close relatives, including rudeness, aggression, frequent conflicts, and even family breakdowns, which can lead to separation from their children. A survey found that many women fear disclosing their diagnosis due to

the potential risk of losing their family. In some cases, husbands or in-laws, particularly mothers-in-law, may prevent these women from interacting with their children. Additionally, women with TB face social barriers, such as difficulties in getting married, and the negative attitudes from family and friends can lead to self-stigmatization. This often results in women interrupting their treatment. These findings emphasize the urgent need for greater awareness and social support to help reduce the stigma around TB, particularly for women.

However, the study conducted after the NGO intervention revealed the following changes in the communities: (1) the spread of false information about TB among the local communities had significantly decreased; (2) the material support of people affected by TB from local self-governments had significantly increased, which directly affects patients' adherence to treatment and contributes to changing attitudes towards people with TB in the communities; (3) almost all interviewed respondents in the group of TB patients had told their family members about their diagnosis themselves. However, in most cases, relatives, after learning about their diagnosis, were morally supportive of the patients and continue to maintain family relationships with them; (4) the number of female TB patients who reported negative attitudes towards them from their husbands and in-laws (mainly mothers-in-law) had significantly decreased. However, self-stigma is still present among female patients, which prevents them from openly discussing their well-being in relation to TB and other comorbidities in the family (according to the estimations of health workers themselves, in the future, patients' increased use of psychological support will significantly reduce self-stigma). Changes were also observed in the attitude of health workers towards TB patients: (1) the dissemination of information by health workers about TB patients' disease among acquaintances and relatives had significantly decreased (previously this point was noted as a reason for increased stigmatization by society and higher levels of self-stigmatization among patients themselves) (2) when communicating with TB patients, health workers had become more interested in the social status of the patient. This, in turn, increases trust in the health worker and increases patients' adherence to treatment; (3) based on the results of the survey in the group of TB patients, it was recorded that some subspecialists motivate them to continue and successfully complete TB treatment.

The Foundation's activities should also be viewed as a social laboratory, where the implementation of the 'Patient School' was successfully tested within inpatient TB medical institutions. Every quarter, dozens of TB patients who switch to outpatient treatment become graduates of the School. This system of patient education has proven its importance as an element of socialisation of TB patients, as well as a mechanism for integrating medical organisations and local governments into the overall activities to support patients at risk of discontinuing treatment. As a result, the Patient School case study was recommended for implementation in all regional TB inpatient medical institutions. The further implementation of the 'Patient School' at the national level will not only strengthen patient adherence to treatment but also enhance the involvement of local authorities in TB-related activities. Additionally, the introduction of artificial intelligence into the psychological support programme for TB patients is a significant advancement. The motivational and information system developed by PF Door is a unique and innovative product, representing the first of its kind in Kyrgyzstan. It is not just a technological innovation, but also a significant step in the field of public health and psychological support. The virtual psychologist has been developed using advanced artificial intelligence and machine learning technologies, which allows it to not only provide qualified psychological support, but also to adapt to the individual needs of each user. It is designed to motivate patients to continue TB treatment and achieve full recovery by reminding them of the importance of following medical recommendations. At the moment, the chatbot can maintain a conversation on various topics, becoming not just a psychologist, but also a virtual friend who can give advice on various issues, such as how the patient can better plan their day. The virtual psychologist is the result of joint work by specialists in the field of artificial intelligence and psychologists, striving to apply the latest achievements of science and technology to improve people's quality of life. It has broad development prospects. In the future, with sufficient funding, PF Door plans to expand the functionality of the virtual psychologist, including the introduction of the Kyrgyz language for communication, which will make the chatbot available to even more users in Kyrgyzstan.

The sustainability of NGO intervention in TB activities can be defined by the following points. Firstly, strategic documents such

as the “TB-free Naryn Oblast” Strategy and the “TB-free Jalal-Abad Oblast” Strategy have been adopted, which are supported by approved schedules for the implementation of activities. The adoption of these strategies at the level of state government testifies to the intention of the oblast leadership to implement TB activities with the active involvement of district administrations and LSG bodies. Secondly, oblast and district administrations, as well as LSG structures, have begun to come forward with their own initiatives aimed at TB detection, prevention, and treatment.

On the basis of the above, it should be concluded that NGOs, given the current challenges and realities, are capable of assuming the role of strategic coordinator of the ongoing processes in all regions of Kyrgyz Republic.

