

11. How NGOs Help Patients with TB Treatment and Contribute to Better Treatment Outcomes: An Overview of the Experience of the Implementation of Alternative Controlled Treatment Alternatives Project

Introduction

Tuberculosis (TB) is one of the socially significant infectious diseases that attracts enormous attention worldwide. The burden of tuberculosis in the Kyrgyz Republic is constantly decreasing, as evidenced by morbidity and mortality rates. Nevertheless, Kyrgyzstan remains one of the 30 countries with a high burden of drug-resistant TB in the world and one of 18 high-priority countries in the World Health Organization (WHO) European Region.

WHO's strategy to eliminate tuberculosis by 2035 (The End TB Strategy)¹ requires the implementation of an array of biomedical, public health, and socioeconomic interventions, often beyond the health sector, as well as major advances in research and innovation to accelerate disease reduction.² The Strategy aims to halt the global TB epidemic by 2035, including reducing TB mortality by 95 % and TB incidence by 90 % compared to 2015. One of the four principles

1 WHO (2015): The End TB Strategy. Switzerland, Geneva: WHO Document Production Services. www.iris.who.int/bitstream/handle/10665/331326/WHO-HTML-TB-2015.19-eng.pdf?sequence=1

2 WHO (2018): WHO compendium of guidelines and standards: ensuring optimal delivery of health services to patients with tuberculosis. 2nd ed., Geneva: World Health Organization. www.iris.who.int/bitstream/handle/10665/273678/9789244514108-rus.pdf

of the Strategy is close collaboration between civil society organisations and local communities; another is the protection and respect of human rights, ethical standards, and the principle of justice.

The National Tuberculosis Program (NTP) of the Kyrgyz Republic has always taken an active position in the implementation of all WHO recommendations, actively introducing progressive methods and innovative approaches in the diagnosis and treatment of tuberculosis. Especially intensive development of the NTP has been achieved in the last seven years; with the support of international projects and programmes, a number of changes have been implemented: new diagnostic methods have been introduced, access and time for obtaining laboratory test results have been expanded, a unified information system for all TB services has been integrated, a case management approach has been applied in primary healthcare, etc. For the first time, not only public health organisations, but also private healthcare providers and non-governmental organisations have been involved in the TB problem.

In Kyrgyzstan, the history of non-governmental organisations in the implementation of TB activities began relatively recently—in 2017, although certain prerequisites for the involvement of NGOs in the provision of TB-related services have been in place for a long time. Today, there are both local and international NGOs working in the field of TB, and they can be conditionally divided into three groups:

- (1) Organisations founded by communities of people with TB—“TB People” in Bishkek, “Plus Center” in Osh oblast, and “Ulukman Daryger” in Issyk-Kul oblast; these NGOs are focused on providing services primarily related to care and support for people with TB, with the patient’s interests at the forefront. The main task is to ensure a patient-centred approach to service delivery and the protection of patients’ rights.
- (2) Organisations founded by professional societies— Kyrgyz – Netherlands community of volunteers – KG (KNCV KG), the Hospital Association, the Nurses Association, etc. The mission of these organisations is to promote innovative, strategically significant changes. Usually their interventions are related to systemic issues. These organisations can implement various

projects aimed at introducing new approaches and practices in TB diagnosis and treatment. For example, the NGO KNCV KG provided technical, advisory, and supervisory support to the national programme in introducing new regimens and drugs to treat drug-resistant TB, while the Hospital Association developed and implemented a system for transporting pathological material, assisted in the implementation of the roadmap for transition to outpatient treatment, etc.

- (3) Organisations that are founded for specific purposes and may include both representatives of professional communities and people affected by TB—the Association of Legal Persons “Partner Network”, established to advocate for and protect patients’ rights; AIDS Foundation East-West (AFEW), which works to overcome legal barriers; Soros Foundation-Kyrgyzstan, which has implemented a legal component to provide legal aid to people affected by TB; and the National Red Crescent Society, which has a charitable function and engages health workers and community volunteers to support TB patients. These NGO activities have been divided into different components of the national program’s implementation, depending on the specialty and capacity of each organization.

This chapter reviews the experience of involving non-governmental organisations in the implementation of a patient education and counselling component to increase adherence to treatment, prevent treatment dropouts among people with TB, and return those lost to follow-up to treatment. The chapter also provides an overview of the experience gained by two organisations funded under a Global Fund grant in implementing above mentioned components, the results achieved, the success stories, and the lessons learned.

Organisation Description

The Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) projects have been implemented in the Kyrgyz Republic since 2004, and until 2023 the assistance provided to the country to fight the three diseases amounted to more than USD 180 thousand. From 2005 to 2011, the Global Fund (GF) grants were implemented

by national partners, namely the Republican AIDS Center and the National Center for Phthisiatry. Starting from 2011, the management of the GF grant was transferred to the United Nations Development Programme (UNDP), and to date the UNDP has been the principal recipient of the grant, i.e. it receives Global Fund funds, implements activities approved in agreement with the GFATM, coordinates programme implementation, including oversight of sub-recipients, and periodically reports on progress, as well as requests for further funding. Initially, all Global Fund grant funds allocated for TB control were used for the procurement of drugs, reagents, equipment, and financial support for medical staff and patients, and services were provided only within the health system. At the same time, in the HIV component, non-governmental organisations were actively involved in various activities aimed at the prevention, detection, and treatment of HIV among vulnerable groups, as well as at supporting these groups, proving their effectiveness in achieving common goals to overcome the HIV epidemic. In 2017, under a Global Fund grant, non-governmental organisations were engaged for the first time to provide services related to supporting people with TB.

This chapter presents the experiences and results achieved by two organisations: the National Red Crescent Society and the Plus Center Community Foundation.

The National Red Crescent Society (NRCS) is the oldest non-governmental organisation in the Kyrgyz Republic, registered in 1926. Currently, the organisation implements projects in the field of healthcare, social assistance, emergency management, and organisational development. The NGO reaches more than 300,000 beneficiaries annually and operates throughout the country. NRCS started implementing the project under the Global Fund grant in August 2018. More detailed information about the organisation can be found at <https://www.redcrescent.kg/ru/>.

The Public Foundation “Plus Center” was registered in 2008 and carries out its work in Osh city and Osh oblast. The PF was established to help reduce the spread of infectious diseases such as HIV, tuberculosis, and hepatitis, as well as sexually transmitted infections, among the population through the implementation of harm reduction and demand reduction programmes for psychoactive substances; the promotion of healthy lifestyles; the demarginal-

isation of psychoactive substance users, homeless people, sex workers, former prisoners, and other marginalised groups; the rehabilitation of people with addictions, as well as their socialisation and re-adaptation; and stigma reduction. Since 2008, the Foundation has worked in the field of HIV and drug use and drug demand reduction programmes. In 2020, the project received its first GF grant for the implementation of a patient-centred approach for patients with drug-resistant TB; in 2023, the organisation also started to provide shelter services for people with TB, as well as work in the field of early TB detection among vulnerable groups.

Description of the Situation at the Beginning of the Project

Tuberculosis is a curable disease, but its treatment has its own conditions: it is a long process that involves taking a combination of anti-TB drugs (sometimes up to 20 tablets) every day. The peculiarity of tuberculosis is that the pathogen reacts very quickly to drugs, and in case of inappropriate therapy, drug resistance occurs. Therefore, the concept of directly supervised treatment (DST) under the supervision of a healthcare provider has been developed for the treatment of tuberculosis. The goal of DST is to ensure that (1) the patient does not interrupt treatment; (2) his or her condition improves; and (3) if they occur, side effects are promptly detected and managed. It is easy enough to ensure DST in hospital settings, but when a patient goes on ambulatory treatment and several factors start to combine—improvement in general health, staying off medication, lack of daily regimen, and freedom of movement—patients tend to discontinue medication.

In Kyrgyzstan, the issue of adherence to treatment has always remained acute. Up to and including 2017, when the project discussed in this section was implemented, the situation was as follows:

- Treatment success for susceptible TB (six months of treatment) was 82 %; about 600 people (10 %) interrupted treatment annually.
- Treatment success for drug-resistant TB (DR-TB) was 52 %,

treatment duration was 24 months, loss to follow-up was 250 people in the annual cohort (i.e. up to 23 % of people with DR-TB interrupted treatment), and treatment success for people with extensively drug-resistant TB was only 17 %.

- In 2017, the introduction of new treatment regimens for DR-TB (new and repurposed TB drugs, short-term treatment regimens) was piloted in the country, and programmatic implementation of new regimens across the country began in 2018. This marked a new era in TB treatment, as a proportion of patients with drug-resistant TB were able to be treated for nine, twelve, or eighteen and twenty fourth months, the new drugs were generally easier to tolerate and improvement happened faster, but treatment required careful monitoring of drug regularity, patient status, and unwanted treatment.
- More than 90 % of patients started treatment as inpatients and switched to ambulatory treatment in the third to sixth months. At the same time, there was virtually no monitoring of drug intake in primary healthcare, drugs were widely dispensed by hand, and treatment was uncontrolled.
- The healthcare system lacked support mechanisms for patients in special, difficult life situations. For example, there was no mechanism to organise home treatment for a bedridden patient; if several people in a family were on treatment, they all had to travel to and from the DST office every day, wasting time and money; persons with no fixed abode could not remain committed to treatment as they moved around the city or even the country; and there were no mechanisms for transferring patients from one healthcare facility to another.

Thus, treatment control was a priority. According to data collected during the GF/UNDP Effective HIV and TB Control project, about 20 % of patients with drug-resistant TB (DR-TB) on ambulatory treatment have one or more factors that increase the risk of treatment dropout. During the fieldwork, there were numerous instances where a patient was discharged from inpatient care having shown significant improvement, but after three to six months of ambulatory treatment, was readmitted to inpatient care with serious deterioration. In particular, the story below characterises a situation that was common at the time.

How patients died without treatment control

A 16-year-old girl, Mira (name changed), came from a family where several people had already died of TB. Mira was also diagnosed with extensively drug-resistant TB (DR-TB), but the extent of the infection was relatively limited. In 2018, the patient was enrolled for treatment at one of the regional TB centres. At that time, new drugs for the treatment of XDR-TB were already available, and the girl was prescribed an effective treatment regimen, which immediately began to bring good results. Three months after starting treatment, Mira showed significant improvement and was discharged from the hospital to ambulatory treatment in one of the remote district centres. Three months after discharge, the patient's X-ray and microscopy/seed results were presented to the regional consultation to monitor the effectiveness of the treatment: the X-ray showed a serious deterioration compared to the image taken at discharge, and later the microscopy and seeding results showed a resumption of bacterial discharge (reversion). A team of doctors went to the family medicine centre (FMC) and to the girl's home to find out the reasons for the deterioration, since at the stage of introduction of new regimens and drugs, each case of treatment with new drugs was under the control of the regional and republican DR-coordinators. After investigation, it turned out that the girl was given the medicines on hand for up to 14 days with the condition that she would take them under the supervision of her mother (a nurse in one of the institutions of the district). The medical staff of the district FMC and the TB office did not control the use of drugs. After a long discussion, the patient pulled out a bag of medication from under her mattress; it turned out that she had first partially and then completely stopped using the medication, and her mother had no influence on her decision. As a result of the interruption in therapy, the girl's condition deteriorated to such an extent that re-hospitalisation was required; Mira was connected to an oxygenator, but in the end the patient could not be saved and died of TB.

Project Model Description

In such a situation, when on the one hand it was critical to provide truly controlled treatment for people with DR-TB, especially for those who received treatment with new drugs, and on the other hand the healthcare system lacked resources to organise NCT, there was a strong need to create an alternative model of controlled treatment.

Until 2017, separate projects aimed at building adherence to treatment in TB patients Médecins Sans Frontières (MSF) and KNCV

through case management were implemented in Kyrgyzstan in pilot mode. These projects were costly, were based on continuous observation of the patient by a case manager, regular patient visits, and provision of substantial material support as an incentive, and could reach only a small number of patients. The Global Fund grant did not have such resources, and the challenge was to find an optimal model that would ensure good adherence to treatment and optimal cost. Taking into account the challenges faced, lessons learned from the GF grants, and lessons learned from other pilots, UNDP developed a model that was implemented first by the NRCS in Bishkek (August 2018-December 2022) and then in Osh and Osh oblast (January 2021-present).

The main goal of this model is to identify all TB patients at risk of treatment discontinuation in a timely manner and to conduct intensive communication with them to identify their needs and address barriers to continuing TB treatment to prevent interruptions or complete discontinuation of use of drugs. Practice has shown that the vast majority of treatment discontinuations can be prevented by improving communication between the patient and the healthcare provider responsible for treatment. The main reasons for treatment discontinuation are 1) poor tolerance of medications, adverse events that are delayed in recognition, and late treatment; (2) poor understanding of treatment steps, including reasons for prescribing a large number of medications, duration of treatment, regularity of check-ups: after improvement of the condition, patients think that they are already cured, while the duration of treatment is explained by illiteracy of doctors, clinical trials, and other myths, which leads to self-discontinuation of treatment; (3) the need for the patient to visit their doctor (Yuranova et al. 2013); and (4) the need to take care of the patient's condition (Toktotonova 2016).

As noted above, directly supervised treatment in a healthcare organisation should theoretically provide the right level of communication and promote adherence. However, the actual situation was quite different. Therefore, the task of the NGO was to organise regular communication with DR-TB patients on treatment in order to determine the degree of risk of treatment dropout and, depending on this, to build further interaction.

The model is based on a three-tiered approach to working with patients with drug-resistant TB depending on their risk of treatment

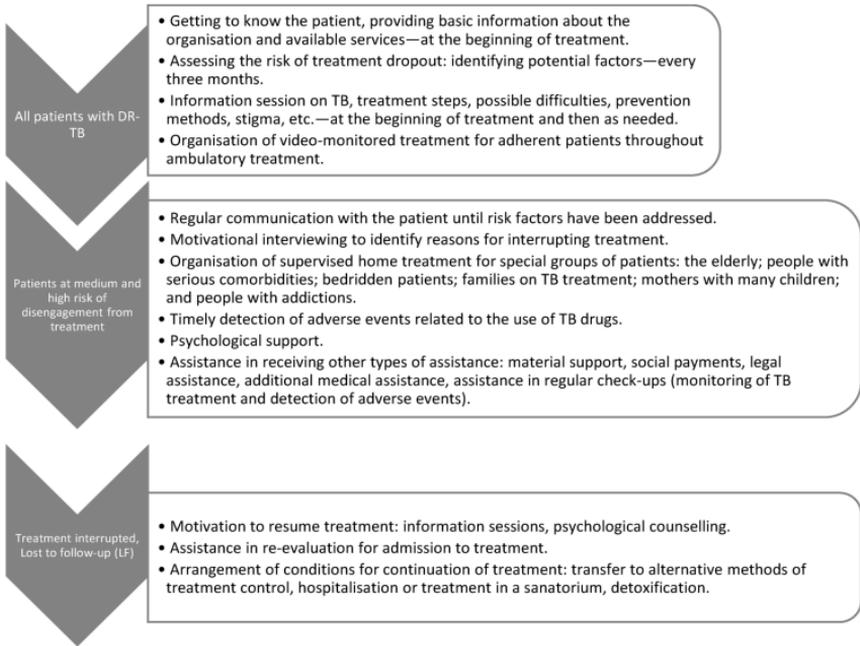


Figure 1: Service delivery model under the GF/UNDP grant

discontinuation: services are divided into basic and extended services, and a group of people with TB who have already discontinued treatment is emphasised (Figure 1).

Implementation Process

The National Red Crescent Society started to implement this model in Bishkek in August 2018. At that time, about 100–120 people with DR-TB were receiving ambulatory treatment in Bishkek city at a time. Despite the possibility to receive at the level of district FMCs, almost all patients came to the City Tuberculosis Control Center (CTCC) daily to get drugs. The project involved one project coordinator, one monitoring and evaluation (M&E) specialist, four case managers with transportation facilities, and one psychologist who was assigned an office in the CTCC building.

Project staff obtained information on DR-TB patients under treatment at the CTCC from district TB doctors and conducted a joint initial assessment of the risk of disengagement. They then met

the patients themselves, conducted a second risk assessment based on an in-depth interview, did a needs assessment, and provided a basic package of services. All patients at medium and high risk of disengagement were taken under case managers' care, i.e. they were provided with an enhanced package of services tailored to their needs.

Care of the patient meant that case managers maintained contact with the patient at least once a week through phone calls, but more often through home visits. At the patient's request, the case manager was able to organise home treatment, i.e. medication was delivered to the patient's home weekly, and medication use was monitored daily by video-controlled treatment via What's Up at a time convenient for the patient, either by direct call or by sending a video of medication use. During the What's Up call, information about the patient's well-being, occurrence of side effects, and other problems was collected from the patient. At the follow-up visit, the case manager would recalculate the remaining medication and assess the patient's overall physical condition. In case of adverse events, the case manager organised immediate communication between the attending physician and the patient, which allowed for timely identification and management of adverse events. Using the organisation's own resources, the CTCC provided humanitarian assistance to those in need. In addition, patients had the opportunity to receive legal and social assistance and help with restoring documents and receiving social benefits and pensions. Case managers transported patients in need to healthcare organisations to receive additional medical care or undergo monthly check-ups to monitor treatment.

Thus, about 100–120 people with DR-TB were under the organisation's care at one time, about 50 people received supervised treatment at home (including video-call) on a quarterly basis, and about 20 of the organisation's clients received additional assistance (social, legal, etc.).

This approach proved to be effective and successful: in Bishkek city, the loss to follow-up after six months of treatment (official terminology for treatment dropouts) decreased from 27 % per quarter to 2%–3 % and throughout the project implementation, even during the Covid-19 pandemic, did not exceed the target of 10 % (Figure 2). Treatment success among DR-TB increased from 46.5 % in the 2016 cohort to 71 % in the 2018 cohort, while the loss to follow-up in

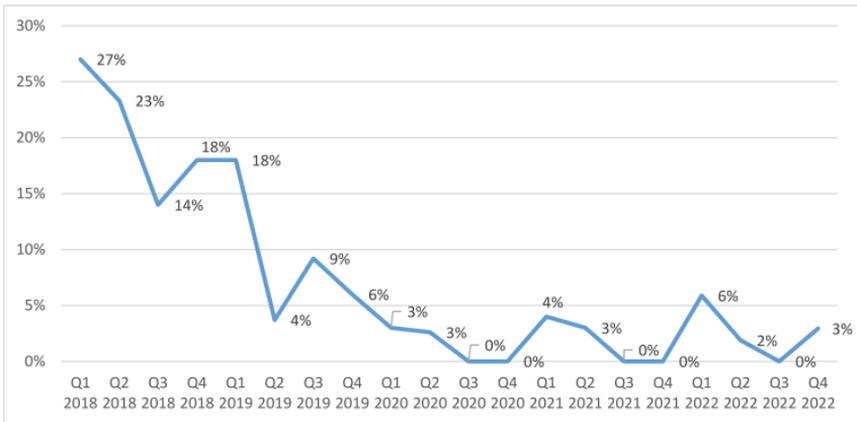


Diagram 1: Percentage of cases lost to follow-up after six months. Treatment, Bishkek city

the annual cohort after full treatment decreased from 30 % (2016) to 21 % (2018). In 2020, when the country was under a coronavirus state of emergency and the health system was fully reoriented to address the disease, the vast majority of DR-TB patients in Bishkek remained adherent and on treatment. The treatment success rate in the Bishkek 2020 cohort was 79.5 % and the loss to follow-up in the entire cohort was only 7.5 %.

A similar model was implemented by the NGO Public Foundation “Plus Center” in Osh city and Osh oblast. The project was launched in January 2021 and was marked by certain difficulties. Initially, health workers at the Primary health care (PHC) level were negatively inclined to cooperate with the NGO, and it took time to overcome distrust and establish constructive work. One of the distinctive features of the work in Osh was that among the organisation’s clients were many migrant workers who work in Russia. As a rule, they are the only breadwinners in large families, and very often, as soon as there is an improvement in their condition, migrants again go to work outside the country. The existing regulatory framework of the Kyrgyz Republic and the Russian Federation does not allow the provision of remote TB treatment, so such patients, having interrupted treatment, are doomed to death in the long run. It is practically impossible to prevent their departure, and this was a serious challenge for the organisation. Despite the fact that there are no official regulations, NGO “Plus Center”, together with doc-

tors, managed to organise controlled treatment in Russia for several people: Patients who had 2–3 months remaining before the end of their treatment, but who expressed a strong intention to leave for the Russian Federation before completing it, applied for treatment through community assistants. The community assistants (usually family members) received medications for 30 days every month and sent them to their clients in Russia, while the NGOs monitored the use of the medications daily by calling What's Up to find out how they were feeling and if they had any adverse events. At the end of treatment, migrants underwent X-rays at their place of residence to determine the outcome, and the result of the X-rays gave them the outcome “treatment completed”. Although this approach is not yet supported by the legal framework, it has prevented eight people with DR-TB aged 18–40 years from dropping out of treatment and thus saved young lives.

The results for Osh city are also impressive: for 2022–2023, not a single DR-TB patient dropped out of treatment within the first six months. According to project data, more than 80 % of the organization's clients who were assigned an outcome successfully completed their treatment.

Review of Factors Contributing to Project Success

Factors that contributed to success include the following:

- **A recognised need for new approaches to TB treatment by the health system:** In Bishkek, good results were achieved more quickly because the management of the TB centre had a good understanding of its capacity and weaknesses, recognised the needs of patients, and was willing to cooperate. Thanks to this, from the first days it was possible to establish a constructive interaction between CTCC, NGOs, and clients of the organisations, synchronise efforts, and work towards one common goal. In Osh, a lot of effort was spent on establishing the cooperation process, which slowed down the process and delayed the first results.
- **The high commitment of NGOs to the mission, goals, and objectives of the project:** NGO staff were both health workers

and people from TB-affected communities, which influenced their commitment, despite relatively low funding (compared to earlier pilot projects).

- **Regular monitoring and evaluation of the process and outputs, flexibility in decision-making and model improvement:** During the project implementation, all processes were monitored monthly, and quarterly meetings were held with all stakeholders. Identified problems were discussed between the implementation team and decision makers, and optimal ways to solve problems were found. Decisions had to be made especially quickly under the constraints of the coronavirus, such as changing the format of service delivery, the ways of interacting with clients of the organisations, etc. For example, the model did not initially envision the widespread use of video-assisted treatment, but analysis showed its greater cost-effectiveness and efficiency, and this became a key element of the project.
- **Client-centeredness:** Initially, the project was client-centred; the NGO's goal was to create conditions in which the patient could continue treatment in acceptable conditions. The range of services varied depending on what needs became relevant at the time. One example is that initially the project did not include a detoxification service for alcohol syndrome, but there was a high demand for this service in Bishkek (one to two cases per quarter) and as a result, this service was introduced into the project. The lack of temporary residency centres (TRCs) for persons without permanent residence also posed a significant challenge for retention of certain categories of patients, resulting in the opening of a TRC in Bishkek in 2021 and in Osh in 2022.
- **Advocacy and service promotion:** Showcasing the results of NGO work at different levels helped convince national stakeholders of the importance of NGOs in providing TB treatment-related services, particularly in case management, dropout prevention, and return to treatment. In 2023, the National TB Program reported to WHO for the first time on NGO performance, and also launched a state-social commissioning: for the first time, NGOs were commissioned by the government to carry out return-to-treatment work. Convincing achievements also contributed to the adoption of separate normative documents,

in particular the National Center of Phthisiology under the Ministry of Health of the Kyrgyz Republic Order on the organisation of video-controlled treatment. A dialogue on the need to organise access to treatment for migrants was launched.

Conclusions

Non-governmental organisations are recognised as equal partners in the implementation of the WHO strategy to eliminate tuberculosis by 2035. In the Kyrgyz Republic, NGOs have only recently started to play the role of service providers, but they have already achieved results.

One of the main challenges in achieving treatment outcome targets is patient adherence to treatment. Experience shows that most of the reasons for treatment dropout are related to insufficient communication and approaches to organising treatment that are not focused on the needs of patients. In particular, the practice of DST at the outpatient level, adopted before 2017, was unfriendly, and the principle of ICH was violated almost everywhere, leading to poor results for both the healthcare system and for patients.

In 2017, for the first time, the Global Fund to Fight AIDS, Tuberculosis and Malaria grant included funds for NGOs. To implement the project, the GF grant developed a model that aimed to identify all people with TB at risk of treatment discontinuation in a timely manner and conduct intensive communication with them to identify their needs and address barriers to continuing TB treatment to prevent interruptions or complete discontinuation of use of drugs. The model included a three-tiered approach to working with patients, and included a range of services that was largely concerned with ensuring ongoing communication with the patient through alternative controlled treatment options.

The implementation of this approach has been shown to be effective and has made a significant contribution to improving treatment outcomes by reducing the proportion of cases lost to follow-up. Continuous analysis of the challenges and factors contributing to success highlighted a number of conditions that had a positive impact on the achievement of the project objectives, in particular, the high commitment on the part of NGOs to the mission, goals,

and objectives of the project. Constant focus on the needs of clients, rapid adaptation of the service delivery format and approaches to changing needs and conditions, monitoring and evaluation of the process and intermediate results, and advocacy of the NGO's work—all of this resulted in a model that effectively addresses the problems of TB patients and promotes stronger adherence to treatment.

References

- Toktogonova A.A. (2016): Causes of treatment failure among patients with multidrug-resistant tuberculosis in the Kyrgyz Republic. In: *Tuberculosis and pulmonary diseases* 94, No. 12. www.researchgate.net/publication/318903651_CAUSES_OF_TREATMENT_DEFAULTS_IN_THOSE_SUFFERING_FROM_MULTIPLE_DRUG_RESISTANCE_TUBERCULOSIS_IN_KYRGYZSTAN_REPUBLIC/fulltext/59847cb1aca27266ad9a1cfc/CAUSES-OF-TREATMENT-DEFAULTS-IN-THOSE-SUFFERING-FROM-MULTIPLE-DRUG-RESISTANCE-TUBERCULOSIS-IN-KYRGYZSTAN-REPUBLIC.pdf, 26. 06. 2024.
- Yuranova M.A./Ruzanov D.Y./Buinevich D.V. (2013): Analysis of factors influencing the formation of adherence to treatment of tuberculosis patients (literature review). www.cyberleninka.ru/article/n/analiz-faktorov-vliyayuschih-na-formirovanie-priverzhennosti-lecheniyu-bolnyh-tuberkulezom-obzor-literatury/viewer, 26. 06. 2024.
- WHO (2015): *The End TB Strategy*. Switzerland, Geneva: WHO Document Production Services.
- WHO (2018): *WHO compendium of guidelines and standards: ensuring optimal delivery of health services to patients with tuberculosis*. 2nd ed., Geneva: World Health Organization.

