

**OPPORTUNITIES TO ENGAGE  
NON-GOVERNMENTAL  
ORGANISATIONS IN THE TB  
RESPONSE IN BELARUS**



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**Opportunities to Engage Non-Governmental Organisations in the TB Response in Belarus: Analytical report – TB Europe Coalition, 2020**

The goal of this analytical report is to present a brief assessment of the readiness of non-governmental organisations (NGOs) to provide TB prevention, diagnostics and treatment services, and the government's readiness to fully engage NGOs in the provision of TB care in Belarus through the social contracting mechanism.

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## List of Abbreviations

<b>AIDS</b>	acquired immunodeficiency syndrome
<b>BRCS</b>	Belarus Red Cross Society
<b>EECA</b>	Eastern Europe and Central Asia
<b>GF</b>	The Global Fund to Fight AIDS, Tuberculosis and Malaria
<b>HIV</b>	human immunodeficiency virus
<b>MDR-TB</b>	multidrug-resistant tuberculosis
<b>MSF</b>	Médecins Sans Frontières
<b>NGO</b>	non-governmental organisations
<b>SC</b>	social contracting
<b>TB</b>	tuberculosis
<b>VCT</b>	video-controlled treatment <sup>1</sup>
<b>WHO</b>	World Health Organisation

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<sup>1</sup> In the WHO Consolidated Guidelines on Drug-Resistant Tuberculosis Treatment (2019) the term "video-observed treatment (VOT)" is used. This analytical report, however, relies on the terminology typically used in Belarus.



# INTRODUCTION

The key approaches to ensure sustainability of the national tuberculosis (TB) response are based on the implementation of the Global Strategy and Targets for Tuberculosis Prevention, Care and Control after they were approved at the sixty seventh session of the World Health Assembly in 2015.<sup>2</sup>

## 2035 targets:

- 95% reduction in number of TB deaths compared with 2015;
- 90% reduction in TB incidence rate compared with 2015;
- No affected families facing catastrophic costs due to TB.

## 2025 milestones:

- 75% reduction in number of TB deaths compared with 2015;
- 50% reduction in TB incidence rate compared with 2015;
- No affected families facing catastrophic costs due to TB.

In 2019, 1,759 people were first diagnosed with tuberculosis in Belarus. The incidence rate was 18.6 per 100 thousand people and reduced by 43.1% as compared with 2015 (32.7 per 100 thousand people in 2015). Over the last 15 years, the highest mortality rate was in 2007–2008, when 1,000 people died of tuberculosis. The number of TB deaths has since declined; in 2019, there were 215 deaths. Currently, the TB mortality rate is 2.2 per 100 thousand people, which represents a reduction of 46.3 % when compared with 2015 (4.1 per 100 thousand people in 2015).

Belarus' TB services include the implementation of new technologies and patient-centred care, and the development of interdepartmental and international cooperation. Molecular genetic diagnostics are offered in the country which are able to return a TB diagnosis within one day. There are new regimens available using modern drugs, which can be used to treat people with extensive drug resistance and even palliative patients.

Treatment success rate for drug-sensitive TB increased up to 87.6%, for MDR-TB – up to 74.0% in 2019 (in 2018 – 75.5%), with the coverage of patients with HIV-associated TB on antiretroviral (ARV) treatment increasing up to 94%. The number of patients receiving palliative care went down by 36% compared with 2018 (843 – in 2018, 304 – in 2019). Such patients were prescribed with new effective drugs, which contributed to the reduction of the TB burden in general population.<sup>3</sup>

Belarus was one of the first countries in Eastern Europe and Central Asia (EECA), which introduced injectable-free TB treatment. In particular, 600 patients were covered with new drugs and regimens in 2018, 1,016 patients in 2019, and in 2020 the plan is to cover all patients with drug-resistant TB with such regimens.

Belarus is one of 18 high-priority countries for the TB response in the WHO European region and one of the 30 countries with the highest

<sup>2</sup> WHA67 Resolutions [https://apps.who.int/gb/ebwha/pdf\\_files/WHA67-REC1/A67\\_2014\\_REC1-en.pdf#page=1](https://apps.who.int/gb/ebwha/pdf_files/WHA67-REC1/A67_2014_REC1-en.pdf#page=1)

<sup>3</sup> <http://www.rnpcpf.by/ru/novosti/248-24--2020-----.html>



burden of MDR-TB in the world. Belarus is one of three Eastern European countries (together with Russia and Ukraine) with the highest MDR-TB rates among people diagnosed with TB. Today, MDR-TB is diagnosed in 38% of newly diagnosed patients and in almost 60% of those who have received repeated treatment.

Currently, the country is using a mixed TB care model: all patients start their TB treatment in in-patient units, where they stay for the majority of their intensive treatment stage, and then they complete their therapy in outpatient settings.

This model led to high hospital admission rates and long hospital stays among TB patients (including smear-negative TB patients who are less infectious). Almost 100% of TB patients are admitted to hospitals. In 2019, the average time that TB patients spent in hospitals was 46.5 days, and for patients with drug-resistant TB the average duration of hospital stay was 154.4 days.<sup>4</sup>

This situation can lead to a high risk of cross-infection due to the hospital conditions, an excessive number of hospital beds (though it has been reduced), the existing model of TB care and incentive payments received by health workers based on the number of bed-days.

Analysis of the TB programme efficiency in Belarus performed by the World Bank<sup>5</sup> showed that about 70% of the national budget allocated for TB response was spent on in-patient treatment in health institutions.

The first pilot project on people-centred TB care and support based on the WHO recommendations presented in the blueprint of a people-centred model of TB care<sup>6</sup>, was implemented in the Brest Regional TB Treatment Centre in 2018. The focus of the project was on developing outpatient care and reducing the number of hospital beds while retaining the same level of funding.

The experience proved the efficiency of the treatment approaches focused on the person receiving treatment and medical consultations in outpatient settings, with no need to stay away from work, family or social life, while having access to social support services. As a result of the activities carried out in 2018, the number of newly diagnosed TB cases fell by 6.8% (by 10.5% in rural population and by 3.2% in urban population) to 18.6 per 100 thousand people. TB incidence rate including repeated infections fell by 2.4% to 24 per 100 thousand people.<sup>7</sup>

Non-governmental organisations operating in Belarus and cooperating with health facilities also made a big contribution to the TB response. When patients start their outpatient treatment, they come face-to-face with their disease. Here an important role belongs to non-governmental organisations, which help patients in such situations, providing them with social and psychological support, charitable aid, etc.

Outpatient care reforms require further coordinated efforts of all stakeholders (including the Ministry of Health, the Ministry of Labour and Social Protection, the Department of Corrections of the Ministry of Internal Affairs, the Ministry of Finance, regional health departments, and non-governmental organisations) to implement sustainable funding mechanisms and develop a new model to provide medical and social support.

<sup>4</sup> Report of Gennadiy Gurevich, Director of the Republican Scientific and Practical Centre for Pulmonology and Tuberculosis at the meeting to sum up the results of TB service activities in 2019, February 2020.

<sup>5</sup> Optimizing investments in Belarus' Tuberculosis response. Washington DC: World Bank Group; 2017 (<https://documents.worldbank.org/curated/en/915061498581699905/pdf/Optimizing-investments-in-Belarus-Tuberculosis-response.pdf>).

<sup>6</sup> A people-centred model of tuberculosis care: blueprint for Eastern European and Central Asian countries, first edition Copenhagen: WHO Regional Office for Europe; 2017 ([https://www.euro.who.int/\\_data/assets/pdf\\_file/0004/342373/TB\\_Content\\_WHO\\_PRO\\_eng\\_final.pdf](https://www.euro.who.int/_data/assets/pdf_file/0004/342373/TB_Content_WHO_PRO_eng_final.pdf), accessed on 5 June 2018).

<sup>7</sup> Report by Svetlana Krapivina, Doctor of the Brest Regional TB Treatment Centre, National Dialogue for the Development of Partner Cooperation to End TB, Minsk, 6-7 August 2019.



# STATE POLICY AND PRIORITIES IN TB RESPONSE

The key strategic document regulating the provision of TB care in Belarus is part of the National Programme "Public health and demographic safety of the Republic of Belarus" for 2016–2020, approved with an Order of the Council of Ministers of the Republic of Belarus No. 200 dd. 14 March 2016.<sup>8</sup> The National Programme includes seven sub-programmes, with the fourth one aimed at TB prevention, care and support (Tuberculosis sub-programme).

**The goals outlined in the Tuberculosis sub-programme are as follows:**

- a) prevention of TB mortality;
- b) prevention of TB morbidity;
- c) provision of quality medical care to patients with MDR-TB.

An Order of the Minister of Health was issued to approve the documents to ensure sustainability of TB and HIV programmes: Plan to Implement the Concept of Sustainable Development of the HIV/AIDS and Tuberculosis Prevention, Treatment, Care and Support System<sup>9</sup> signed on 21 December 2016 and the Concept of Sustainable Development of the HIV/AIDS and Tuberculosis Prevention, Treatment, Care and Support System<sup>10</sup> dated 21 April 2017.

The Implementation Plan was approved for three years (2016–2018) and covered a number of key issues related to the transition period and sustainability. For instance, it was aimed at developing and updating the regulations to allow the procurement of medical drugs and laboratory supplies from international platforms (i.e. through the Global Drug Facility (GDF)); transition to internal funding in the procurement of TB drugs (new and repurposed drugs) and laboratory supplies for rapid molecular tests; promoting and facilitating registration of new and repurposed TB drugs and coverage of all the costs to maintain and further develop a relevant electronic database.

**The activities stipulated in the plan were performed by 49%.**

**The reasons of under-performance were as follows:<sup>11</sup>**

- excessively big changes planned in the view of the available timeframe, especially in terms of legislation;
- insufficient level of involvement of all the organisations working in the area of TB and HIV in developing and implementing the Transition Plan;
- failures in the choice of implementers and co-implementers;
- lack of priorities in the planned activities;
- lack of clearly defined responsible persons from each implementing partner;
- lack of regular monitoring of the plan implementation;

<sup>8</sup> <http://minzdrav.gov.by/ru/ministerstvo/gosudarstvennye-programmy/>

<sup>9</sup> [https://www.gotkb.by/documents/norm\\_akt\\_ftiz\\_2017/plan\\_konseptia.pdf](https://www.gotkb.by/documents/norm_akt_ftiz_2017/plan_konseptia.pdf)

<sup>10</sup> [https://www.gotkb.by/documents/norm\\_akt\\_ftiz\\_2017/konseptia.pdf](https://www.gotkb.by/documents/norm_akt_ftiz_2017/konseptia.pdf)

<sup>11</sup> Presentation "Results and prospects of implementation of the Plan to Ensure Sustainability of the National Response and Transition to the Government Funding of HIV/AIDS Prevention, Treatment, Care and Support Programmes in the Republic of Belarus", Third International Forum of HIV-Service Organisations, Minsk, 4 December 2018.



- for some activities – complicated and obscure wording of the objectives;
- lack of opportunity to update or correct the plan (at least once a year).

After this plan expired, a new document was developed and approved with an Order of the Minister of Health of the Republic of Belarus dd. 9 March 2020 – Plan to Ensure Sustainability of HIV/AIDS and Tuberculosis Response and Transition to Government Funding of Prevention, Treatment, Care and Support Programmes in the Republic of Belarus in 2020–2021 (Transition Plan).

**Current Transition Plan sets forth the following objectives:**

- implement the social contracting mechanism in TB prevention;
- ensure the full transition to government funding in the procurement of TB drugs, supplies for TB diagnostics, personal protection equipment for the medical staff of TB organisations, etc;
- strengthen cooperation of the state governance bodies and health institutions with non-governmental organisations in assessing the situation with the spread of TB;
- build the capacity of NGOs and the communities of key populations at high risk of TB in exercising their right to health;
- create a national system to train staff members of the NGOs working in TB prevention, treatment, care and support;
- eliminate the barriers in access to TB treatment, care and support;
- develop a mechanism to assess the quality of preventive and socio-medical TB services.

The House of Representatives of the National Assembly of the Republic of Belarus received amendments to the Law "On health care" for review, with a separate chapter dedicated to controlled treatment. In particular, its application to the patients affected by TB.

Despite the fact that the new Transition Plan was developed taking into the account the experience of implementing the previous Transition Plan, with a clearer definition of the roles of responsible implementers and monitoring system, still most activities stipulated in the plan are not supported by funding allocations (as it was with the previous plan). Thus, the scope of its implementation largely depends on the efforts of non-governmental organisations to protect the interests of the target groups. First of all, it relates to the activities aimed at building the capacity of NGOs and communities in TB prevention, treatment, care and support.



# REGULATION OF THE SOCIAL CONTRACTING MECHANISM AND ITS IMPLEMENTATION

Social contracting (SC) regulation is based on two different packages of regulatory documents.

**In the area of social services, social contracting is regulated by:**

- Law of the Republic of Belarus "On social services" dd. 22 May 2000 as amended by the Law of the Republic of Belarus dd. 13 July 2012.
- Resolution of the Council of Ministers of the Republic of Belarus No. 1219 "On some matters of the social contracting" dd. 27 December 2012 (hereinafter – Resolution 1219).

**In the area of prevention of communicable diseases, including HIV, social contracting is regulated by:**

- Law of the Republic of Belarus "On prevention of diseases dangerous to public health, human immunodeficiency virus" dd. 7 January 2012.
- Resolution of the Council of Ministers of the Republic of Belarus No. 1031 "On the matters of social contracting in the prevention of diseases dangerous to public health, human immunodeficiency virus" dd. 28 December 2017 (hereinafter – Resolution 1031).

**Comparative analysis of the social contracting regulations demonstrates that most norms regulating the SC mechanism in those two areas are identical:**

- identical principles of SC implementation; openness and transparency of the procedures, uniform requirements, objective assessment, equal access to information;
- customers – local government bodies;
- implementers – non-governmental non-profit organisations;
- funding sources – local budgets allocated for the implementation of government programmes;
- social contracts are awarded on a competitive basis;
- contracts are signed for a period up to five years within the terms of the state programme's implementation.

However, there are certain procedural differences in the regulation of SC procedures, creating challenges for those participants who implement social contracts in different areas at the same time. For instance, there are different requirements to the list of documents to be submitted; different system to evaluate proposals; different conditions to provide subsidies, etc. Comparison of the key norms of social contracting in the areas of social services and prevention of socially dangerous diseases is shown in Table 1 below.



**Table 1. Comparison of the social contracting norms in the areas of social services and prevention of socially dangerous diseases**

Criteria	Social services	Health services
State customers	Local councils, local executive and regulatory bodies	Regional and Minsk city executive committees
List of services	No list of services	List of services and procedures to calculate the cost of such services are set forth by the Ministry of Health
Conditions to subsidise services	Only salaries and indirect labour charges of the employees providing services are subsidised	Full coverage of costs
Conditions to subsidise projects	Up to 50% of project costs	Up to 80 % of project costs

SC implementation and funding is stipulated to be covered from local budgets in two government programmes:

1. National Programme for Social Protection and Employment Promotion in 2016–2020 approved by the Resolution of the Council of Ministers of the Republic of Belarus dated 30 January 2016 No. 73.
2. National Programme "Public Health and Demographic Safety of the Republic of Belarus" for 2016–2020 (Sup-programme 5 "HIV Prevention") approved by the Resolution of the Council of Ministers of the Republic of Belarus dated 14 March 2016 No. 200.

Resolution No. 1031 defines that the list of services to be provided through the social contracting mechanism in the area of prevention of socially dangerous diseases and HIV as well as the procedure to calculate the costs associated with the provision of such services are set forth by the Ministry of Health.

Though Resolution No. 1031 was approved more than two years ago, the Ministry of Health has not defined the list of services to be provided through the social contracting mechanism yet. Lack of such a list of services set forth by the Ministry of Health is currently the biggest legal barrier on the way of implementing social contracting mechanism in the area of prevention of socially dangerous diseases and HIV.

Another legal barrier appeared through the development of legislation on social services. When the Law "On social services" was updated by adding a chapter on social contracting in 2012, article 30 of the law contained socio-medical services among various types of social services. Socio-medical services were most in-demand and were widely used within the social contracts implemented by the Belarus Red Cross Society (BRCS). In 2018, 53% of social contracts were signed with BRCS.<sup>12</sup>

In 2017, the Law "On social services" was amended, socio-medical services were excluded from article 30 because the delivery of such services is regulated by the Law "On health care". Such amendments

<sup>12</sup> Developing legislation and practice of implementing social contracts in Belarus, Analytical Report, Valeriy Zhurakovskiy, Minsk, 2020.



led to arguments around the fact that the socio-medical services provided by BRCS, which include social and medical services at the same time, can no longer be funded under the Law "On social services" because they are to be funded within the healthcare laws. However, the Law "On health care" does not stipulate a social contracting mechanism. Thus, about half of the services offered within the social contracting mechanism, which include not only social support but also medical services for elderly or senior people who are lonely or live alone, with multiple diseases, mental disorders, cancers or other serious chronic conditions, could lose funding.

Annual growth in the number of contracts and the scope of subsidies provided within the social contracting mechanism proves high demand for such mechanism (Table 2). Since the SC mechanism was launched, the number of contracts signed and the scope of funding provided to NGOs within such mechanism grew almost threefold. Thus, 123 social contracts for the total amount of 903 thousand Belarusian rubles (USD 431.7 thousand) were implemented in 2019.<sup>13</sup>

**Table 2. Number of contracts and amount of subsidies provided within the social contracting mechanism**

	Criteria	2014	2015	2016	2017	2018	2019
Social services	Number of contracts	33	46	53	72	91	115
	Amount of subsidies	BYN 180 thousand (USD 176.2 thousand)	BYN 240 thousand (USD 151.3 thousand)	BYN 300.4 thousand (USD 151.1 thousand)	BYN 415.4 thousand (USD 215.0 thousand)	BYN 567.4 thousand (USD 278.6 thousand)	BYN 754.0 thousand (USD 360.5 thousand)
	Number of beneficiaries	over 850 people		1 610 people	2 637 people	2 820 people	4 695 people
HIV prevention	Number of contracts					10	7
	Amount of subsidies					BYN 91.1 thousand (USD 44.7 thousand)	BYN 149 thousand (USD 71.2 thousand)

The following preventive services are offered through the social contracting mechanism in the area of prevention of socially dangerous diseases and HIV:

- home-based palliative care for people living with HIV;
- consultations for people living with HIV and building their adherence to antiretroviral treatment (ART);
- anonymous preventive consultations for people who inject drugs.

Analysis of the delivery of services to build ART adherence within the SC mechanism in Gomel region showed the efficiency of such services:<sup>14</sup>

- ✓ covered with services – 241 people;
- ✓ undetectable viral load – 83 people (34.4%);

<sup>13</sup> Developing legislation and practice of implementing social contracts in Belarus, Analytical Report, Valeriy Zhurakovskiy, Minsk, 2020. The data was calculated based on the average official exchange rate, with the amount calculated as an arithmetic mean value set by the National Bank of the Republic of Belarus.

<sup>14</sup> Presentation "Peculiarities of the HIV epidemic process in the Republic of Belarus at the current stage", T. Svetogor, Head of the HIV and Viral Hepatitis Prevention Department of the Republican Centre for Hygiene, Epidemiology and Public Health, republican round table "Urgent Issues of HIV Infection", Minsk, 18 March 2020.



- ✓ minimum viral load – 19 people (8%);
- ✓ referred to specialised doctors – 128 people (53.1%);
- ✓ initiated or renewed therapy – 74 people (30.7%);
- ✓ referred for medical examinations (CD4 count and VL)  
– 107 people (44.4%);
- ✓ received employment support – 6 people (2.5%).

Tuberculosis is considered a socially dangerous disease. It affects the most vulnerable people who find themselves in difficult circumstances and require social support based on people-centred approaches. However, despite the needs of vulnerable populations in TB care and support, currently social contracting is not implemented in Belarus in the area of social services and prevention of socially dangerous diseases among people with TB.

The main reasons for such situation is, on the one hand, the lack of activities stipulating social contracting in sub-programme "Tuberculosis" of the National Programme "Public Health and Demographic Safety of the Republic of Belarus", and on the other hand, insufficient efforts of NGOs to protect the interests of people with TB in receiving TB care and support services through the social contracting mechanism.



# THE ROLE OF NGOS IN TB RESPONSE

As of 1 January 2020, there were 2,995 NGOs and 43,545 units of NGOs registered in the Republic of Belarus.<sup>15</sup>

The most active NGOs working in the area of TB response are the Belarus Red Cross Society, Médecins Sans Frontières and Public Association "Defeat Tuberculosis Together."

## **Belarus Red Cross Society (BRCS)**

BRCS has been implementing projects to provide support to people with tuberculosis for over 10 years.

The services offered by BRCS are aimed at people with drug-resistant TB who receive long-term (from 12 to 24 months) treatment and have to take several TB drugs every day.

In this category of patients, there are often people with low treatment adherence, people who refuse treatment or have treatment deficits, patients with co-morbidities (alcohol abuse, HIV, hepatitis C) and socially vulnerable people – those who release from places of confinement, homeless people, unemployed and migrants. People who have tuberculosis experience high stress levels due to the loss of employment and family links, stigma from society, and the need to take a lot of medications every day.

BRCS works with people who have TB to build and retain their treatment adherence and uses various methods of motivation to ensure the success of TB treatment in all the regions of Belarus.

BRCS staff members have been involved in organizing video-controlled treatment of people with TB since its launch in 2016. Such form of outpatient treatment means that patients do not have to visit their doctors six days a week to take the required medications while doctors observe the process. It is enough to make a video report and send it to the doctor via internet. BRCS provides patients with mobile phones to make video recordings and send them to health workers if they do not have such phones. In 2019, over 200 patients with drug-resistant tuberculosis received video-controlled treatment.

Besides, BRCS supports treatment adherence in patients at the outpatient treatment stage, providing them with travel cards or reimbursing their transportation costs.

BRCS engaged over 100 volunteers to provide psychosocial support to people with tuberculosis via telephone.

In 2019, BRCS procured over 600 travel cards, which were distributed among 167 patients, 205 patients received reimbursement of transportation costs, 253 people were enrolled in video- controlled

<sup>15</sup> [https://minjust.gov.by/directions/compare\\_coverage/](https://minjust.gov.by/directions/compare_coverage/)



treatment programmes, and 54 – in the individual support programme run by a multidisciplinary team. Over 500 patients received psychological and social support.

Starting from 2019, BRCS has been implementing a pilot case management project in Brest, Vitebsk, Gomel, Grodno and Mogilev regions. The model stipulates individual medical and social support by multidisciplinary teams: a doctor, a nurse, a psychologist, a social worker and a peer consultant (someone who had an experience with TB and can share such experiences). The main goal of case management is to provide support to the patient from the first day of their hospital stay and up to the last day of TB treatment course. Within case management, patients with TB receive support in getting legal counselling and services, help from psychiatrists, drug treatment specialists and infectious disease doctors, access to medical examinations and treatment, support in finding jobs, resolving their housing or other problems, and psychological and informational support.

Currently, BRCS has 52 staff members working with people affected by TB, including medical and social workers, psychologists and experts. There are permanent volunteer groups actively working in all regions bringing together 108 volunteers.

Traditionally, BRCS helps people from vulnerable populations with clothes, footwear, food products and hygiene kits.

The pilot project is implemented by BRCS within the GF programme, using the approaches of Médecins Sans Frontières in its activities.

## **Médecins Sans Frontières (MSF)**

Médecins Sans Frontières started working in Belarus in 2015. Today, representatives of this organisation work in four TB treatment centres of the country.

Their activities are aimed at supporting treatment adherence in patients with alcohol abuse disorders and marginalised populations as well as providing support in accessing new TB drugs, including bedaquiline and delamanid.

Currently, Médecins Sans Frontières work on non-injectable substances, which would allow patients to receive treatment at home. Additionally, clinical trials are currently in process to introduce a treatment regimen for drug-resistant tuberculosis, which would last six months instead of two years.<sup>16</sup>

## **Public Association "Defeat Tuberculosis Together"**

In 2003, the community of people affected by TB founded a Public Association "Defeat Tuberculosis Together" aimed at providing comprehensive help and support to people diagnosed with TB, those who have had an experience with TB and their family members.

Since the start of its activities, the NGO has been working on promotion of the transition to people-centred care models as well as reduction of stigma and discrimination against people affected by TB in society.

<sup>16</sup> <https://1prof.by/news/obshchestvo-i-profsoyuzy/dlya-lecheniya-tuberkuleza-s-shirokoj-lek/>



Patient groups were created bringing together people with the same problem motivated to resolve it at a certain territory.

## **TB patient communities**

An important role in improving the quality of life of people with HIV and TB belongs to the patient communities, who together fight for the rights of the populations vulnerable to HIV and TB, counter stigma and discrimination, and monitor the quality of the services provided.

Community representatives are members of the standing coordinating body – Country Coordinating Committee on Cooperation with the Global Fund to Fight AIDS, Tuberculosis and Malaria – which ensures interaction among governmental, non-governmental and international organisations in managing the national programmes aimed at HIV/AIDS and TB response. In 2019, a National Platform of the Key Populations Affected by HIV and Tuberculosis was created.

## **Raising funds for public health activities**

The main source of funding for Belarusian NGOs working in the area of HIV and TB prevention used to be the support provided by the Global Fund to Fight AIDS, Tuberculosis and Malaria, which is reduced year after year.

In recent years, NGOs have been focusing more on raising funds inside the country through the development of crowdfunding.<sup>17</sup> A good example of such an approach is the campaign to raise funds in response to COVID-19 epidemic. Only in the first two months of COVID-19 epidemic, over three million US dollars were raised in Belarus to support the health care sector, with volunteer support offered to health workers and the most vulnerable populations.

However, access to funding is still one of the most burning issues for the NGOs in Belarus. According to the Decree of the President of Belarus No. 3 "On foreign charitable aid" dd. 25 May 2020, foreign charitable aid is subject to mandatory registration at the Humanitarian Activities Department of the President's Administration. To register the funds received, NGOs need to have an official letter issued by a competent body confirming that the targeted use of funds has been approved as well as showing the rationale for tax exemption. There is a fee to be paid for the registration of foreign charitable aid – 0.5% of the amount of such aid, which is not exempt from charges, taxes and duties. The Order of the President of the Republic of Belarus "On the provision and use of charitable (donor) aid" No. 300 dd. 1 July 2005 defines a closed list of acceptable goals, for which NGOs can get funding from business companies in Belarus. Public associations are not allowed to carry out any commercial activities, i.e. get paid for their services.

All those restrictions on raising funds from non-governmental sources do not contribute to the sustainable development of non-governmental organisations working on the TB response. Launching the social contracting mechanism in the provision of comprehensive socio-medical support to people affected by TB by NGOs would allow increasing the sustainability of such support.

<sup>17</sup> Crowdfunding (from "crowd" and "funding") means collective cooperation of people who volunteer to combine their money or other resources through the internet to support the efforts of other people or organisations.



# NEEDS OF THE POPULATIONS AFFECTED BY TB, WHICH CAN BE THE SUBJECT OF SOCIAL CONTRACTING

In order to effectively plan the services to be provided within the SC mechanism, it is necessary to carry out a needs assessment to define where, when and which services should be provided to certain groups of people affected by TB.

The main objectives of needs assessment:

- obtain information about the current situation of certain populations – their problems or needs in services – and define the resources and approaches to resolve such problems or satisfy such needs;
- define satisfied and unsatisfied needs in services among target populations. Satisfied needs refer to the services which target populations already use (existing, available, meeting their needs). Unsatisfied needs refer to the services, which are not yet provided by organisations (do not exist, are not available or do not meet the needs of target populations);
- develop conclusions and recommendations to improve the existing services and develop new services in line with the needs identified.

Usually, needs of the key populations, including people affected by TB, in prevention services are assessed through qualitative studies when preparing country proposals to be submitted to the Global Fund to Fight AIDS, Tuberculosis and Malaria. Such studies give us the main information about the needs of people affected by TB.<sup>18</sup>

Currently, people affected by TB are provided with free treatment, while social support is more of an exception than a rule.

*«I did not get support from any organisations».*<sup>19</sup>

*«I can say nothing, I did not receive help from anyone».*

*«MSF provided some kind of humanitarian aid, in the hospital they gave us underwear, socks, shaving cream, toothpaste, shampoo, Gillette shaving sets. For us not to get bored they also brought pictures, a volleyball net and balls. That's what MSF procured. They brought the humanitarian aid. That's it, I don't think we received anything else».*

*«I got a phone through the Red Cross. My phone was okay, but it did not support Skype. They also give some food products».*

The range of unsatisfied needs of the target group is very big. The needs of the target group are differentiated, first, depending on the

<sup>18</sup> Assessing the needs of key populations in prevention services provided at prevention sites to be included in the country proposal to the Global Fund to Fight AIDS, Tuberculosis and Malaria in 2019–2021 in the Republic of Belarus. Study report, Evgeniya Kechina, Doctor of Social Studies, Prof., Minsk, 2017.

<sup>19</sup> Hereinafter in italics you will see quotes from people affected by TB, who were randomly selected from Minsk, Gomel, Svetlogorsk, and Mozyr, illustrating their needs in social support, which they raised during focus group discussions and individual interviews.



treatment stage (inpatient, outpatient, after treatment completion) and, second, they cover not only the target group members, but also their family members (children who live outside their homes while their parents receive treatment; patient's relatives).

*«Most difficult? Realising that I had tuberculosis was most difficult for me. I got hysterical when I heard I had tuberculosis. The first month after you find out you have tuberculosis is the hardest one. Each stage has its own difficulties».*

*«Working with the families. The family should be prepared by a specialist to a situation when their father, brother or whoever will be on treatment for a very long time and they will face all those problems».*

*«My mother was very worried that she will get infected and she will be fired from work (she works as a cook at a nursery school). Many people are afraid and I understand them because ignorance leads to fears. People are afraid of this disease, they are worried about their health. It is a very big problem, you face a huge barrier, when you meet new people and say you have tuberculosis».*

Currently, TB patients need different types of social support (financial, informational, psychological, legal) at different stages of their treatment and after treatment completion to resolve the wide range of problems they face.

*«I talked to people from a non-governmental organisation and only then I learned that I will remain on the register for 18 more months. Though I couldn't get it why some other people can know it and I can't».*

*«The main thing is that there should be psychologists in health institutions to make people believe in something. You can kill or cure a person with just one phrase».*

*«Lack of knowledge among patients about what rights they have».*

*«I don't get it how I can work. Where can I work? How can I make my living?! Please find me a job».*

Another important need, which has been identified, is the need for social activities for TB patients during their long-term hospital stay, e.g. leisure activities. One of the key problems during long-term inpatient treatment is that people are isolated from their social activities and their life is limited within hospital walls, which negatively affects their mental state. That is why social support, alongside with medical help, is important as it improves the psychological and emotional state of the patients and improves their motivation to continue with treatment, making treatment more effective and successful.

*«When you are at the hospital, there is a lack of physical exercise. I even told my doctor that it was hard, there was some shortness of breath. I would learn how to breathe correctly. There is nothing to do there anyway».*

*«To be honest, it's not possible for a normal person to be there. That's why probably people go away, run away or some start to lift the elbow because it is very difficult with this crowd when you are sober, so almost everyone is drinking».*



Though the studies, which were held, were not aimed at assessing the needs of people affected by TB in services, which may be provided within the social contracting mechanism, the responses that received within the studies allow making certain conclusions about the needs of TB patients that can be addressed through the social contracting:

Services	Functions (why the target group needs such services)
Building treatment adherence	<ul style="list-style-type: none"> <li>• informing patients about the need to treat TB;</li> <li>• counselling on adherence to treatment, disease progression, terms and criteria of hospital stay, types of treatment depending on the indications (outpatient, inpatient), opportunity to get treatment at the place of residence or stay, not at the place of registration, side effects of TB therapy;</li> <li>• providing psychological support throughout treatment (especially at the stage of diagnosis acceptance, transition from inpatient to outpatient treatment);</li> <li>• peer counselling (providing accurate information through equal trust-based conversations with a trained patient/former TB patient);</li> <li>• self-help groups through the treatment process;</li> <li>• support in access to video-controlled treatment (VCT) and in the course of VCT;</li> <li>• publishing printed materials (leaflets, brochures) for people affected by TB;</li> </ul>
Social support of people affected by TB at all treatment stages	<ul style="list-style-type: none"> <li>• helping to resolve housing or household issues, accessing targeted social support, etc.;</li> <li>• helping to access financial and humanitarian aid (clothes, personal hygiene items, food products, cost of transportation to the outpatient treatment centre, access to phones and communication costs for VCT, etc.);</li> <li>• referring patients to other organisations (medical, social, non-governmental organisations) to resolve their problems;</li> <li>• helping patients to exercise their rights to get help and subsidies from government agencies (payments, technical devices for social rehabilitation, food packages, etc.)</li> <li>• helping to apply for pension or disability status;</li> </ul>
Legal aid	<ul style="list-style-type: none"> <li>• legal aid to patients related to labour law (not letting the employer to fire employees while they are on treatment, support in case of job loss, informing employers that discrimination from the side of colleagues is not permissible, sick leave terms, etc.);</li> <li>• legal aid to students with TB concerning their return to the educational institutions to continue their studies after they are released from inpatient facilities;</li> <li>• legal aid to parents in cases when their children are taken away from them and helping to return their children who were taken by social services;</li> <li>• legal counselling on how to pay for the utility services during hospital stay, how to avoid being included in the database of people not engaged in economy, who have to pay for the hot water, gas and heat supply in full with no subsidies based on Decree No. 1 "On employment promotion" ("social parasitism tax"/"social welfare tax");</li> <li>• legal counselling on the rights of people who find themselves in difficult life situations;</li> <li>• helping to obtain personal identification documents;</li> </ul>
Support to families affected by TB	<ul style="list-style-type: none"> <li>• psychological and social support to children who live outside their homes while their parents receive treatment;</li> <li>• legal and psychological support in cases of discrimination of the patient's family members by other people, in particular at work or school;</li> <li>• providing psychological, legal, informational consultations to TB patients' family members;</li> <li>• publishing printed materials (leaflets, brochures) for those closest (family members) of people affected by TB about the specifics and duration of TB treatment;</li> </ul>
Employment support for people affected by TB	<ul style="list-style-type: none"> <li>• career guidance: assessing the life circumstances and current problems of people affected by TB; assessing their individual skills, abilities, interests and desires; developing an individual rehabilitation and employment plan;</li> <li>• support in getting registered as unemployed;</li> <li>• support in professional training (to master a profession allowing people to earn their living after their experience of TB);</li> <li>• finding jobs; developing the skills of self-presentation to pass interviews with potential employers; helping to build personal contacts with potential employers;</li> <li>• support at work during the adaptation stage;</li> </ul>



Services	Functions (why the target group needs such services)
Social adaptation of TB patients during their long-term hospital stay	<ul style="list-style-type: none"> <li>• improving sanitary and living conditions in TB treatment facilities;</li> <li>• organizing activities/leisure time of patients during their long-term hospital stay;</li> <li>• organizing training activities for TB patients in inpatient settings;</li> <li>• providing psychological support during hospital stay;</li> </ul>
Social support for people with TB released from places of confinement	<ul style="list-style-type: none"> <li>• preparing people with TB to their release from places of confinement;</li> <li>• psychological, legal, informational counselling;</li> <li>• social and medical support of TB patients released from places of confinement while they integrate in society and receive TB treatment;</li> <li>• publishing printed materials (leaflets, brochures);</li> </ul>
Developing tolerance to people affected by TB	<ul style="list-style-type: none"> <li>• awareness-raising activities to build tolerance and reduce stigma towards people affected by TB in the inner circle of such people and in society in general;</li> <li>• training specialists providing services and support to people affected by TB and developing their interpersonal skills;</li> </ul>
Social and medical support of people with TB and co-morbidities	<ul style="list-style-type: none"> <li>• helping people to access consultations of specialist doctors (psychiatrists, drug treatment specialists, infectious disease doctors, etc.);</li> <li>• helping patients to go through medical examinations and receive treatment;</li> <li>• supporting patients in obtaining and administering medications;</li> <li>• providing medical support;</li> <li>• publishing printed materials (leaflets, brochures).</li> </ul>

The existing data does not allow any conclusions to be drawn on the priority needs and on the scope of services people affected by TB need. For this purpose, quantitative needs assessments in the context of social contracting should be carried out to define the priority services and the scope of required funding to be allocated to social contracting.



# KEY CONCLUSIONS AND RECOMMENDATIONS

Despite some positive developments in the epidemiologic situation and organisation of TB care in Belarus, there are still a number of issues related to the high prevalence of MDR-TB. Belarus is one of three Eastern European countries (together with Russia and Ukraine) with the highest MDR-TB rates among people with TB: MDR-TB is diagnosed in 38% of newly diagnosed patients and in almost 60% of those who receive repeated treatment. MDR-TB creates a high burden on the health care systems because its treatment is complicated, lengthy and expensive.

To ensure the transition to the models aimed at effective MDR-TB treatment, a people-centred model of TB care in line with the WHO recommendations was piloted in Brest region. People-centred TB care is focused not on patients or their diseases, but on the needs of people and local communities as well as their healthcare-related expectations. The pilot proved the efficiency of the treatment approaches focused on the person receiving treatment and health consultations in outpatient settings, with no need to stay away from work, family or social life, while having access to social support services. As a result of pilot project in Brest region, the number of all newly diagnosed TB cases fell by 6.8%, in particular by 10.5% in rural population. TB incidence including repeated infections fell by 2.4%.

The experience of Belarus Red Cross Society, Médecins Sans Frontières, and Public Association "Defeat Tuberculosis Together" shows that NGOs play an important role in making sure that TB care is people-centred. Patient communities articulate the interests and needs of people affected by TB. NGOs can support patients to remain in treatment, which contributes to improved treatment adherence and better outcomes. Besides, they play an essential role in other important areas, such as building and maintaining TB awareness in society, countering stigma and increasing community involvement in TB care and support. NGOs are also at the forefront of providing psychosocial support to patients and their families.

One of the mechanisms allowing to engage NGOs in providing comprehensive TB care can be social contracting, which is already implemented in Belarus in the area of social services since 2013 and in HIV prevention since 2018.

Tuberculosis is one of the socially dangerous diseases. It affects the most vulnerable populations who find themselves in difficult circumstances and need social support using people-centred approaches. However, despite the needs of vulnerable populations in TB care and support, currently social contracting is not implemented in Belarus in the area of social services and prevention of socially dangerous diseases among people with TB.

Considering that TB is a socially dangerous disease, social contracting regulations and practices existing in the area of HIV can be fully applied to TB prevention, care and support. The only barrier, not



allowing funds to be allocated to support NGOs working in the area of TB is lack of social contracting component in sub-programme "Tuberculosis" of the National Programme "Public Health and Demographic Safety of the Republic of Belarus".

## Recommendations

The recommendations below can be useful for all stakeholders involved in the development and approval of the TB programmes representing both governmental and non-governmental sectors:

### 1. Legislation

To harmonize legislation and improve SC procedures, it is important to:<sup>20</sup>

- introduce amendments to the Law of the Republic of Belarus "On prevention of diseases dangerous to public health, human immunodeficiency virus" to bring it in line with the lessons learned when providing prevention services and implementing social contracting mechanisms;
- introduce amendments to the Law of the Republic of Belarus "On minimum state social standards" to recognize the services provided through the social contracting mechanism as part of the publicly available social services;
- introduce amendments to the Resolution of the Council of Ministers of the Republic of Belarus No. 1031 "On the matters of social contracting in prevention of diseases dangerous to public health, human immunodeficiency virus" dd. 28 December 2017 to bring it in line with the lessons learned when providing prevention services and implementing social contracting mechanism;
- define the list of services to be provided within the social contracting mechanism, including services for people affected by TB, as well as the procedure to calculate the costs associated with the provision of such services with a Resolution of the Ministry of Health;
- analyse the existing regulations to identify any stigmatizing norms or provisions, preventing access to TB prevention, treatment, care and support services.

### 2. Funding sustainability

To ensure sustainability of services, it is vital to:

- include activities implemented through social contracting mechanism in sub-programme "Tuberculosis" of the National Programme "Public Health and Demographic Safety of the Republic of Belarus" for 2021-2025;
- when preparing country proposals for the main grant of the Global Fund to Fight AIDS, Tuberculosis and Malaria for 2022-2024, include funding of the activities stipulated in the Plan to Ensure Sustainability of HIV/AIDS and Tuberculosis Response and Transition to Government Funding of Prevention, Treatment, Care and Support Programmes in the Republic of Belarus in 2020-2021, which are critical for further development of the social contracting mechanism and which will not be implemented if funding is not available;

<sup>20</sup> Подробный анализ практик применения нормативных актов о ГСЗ и предложений о путях их совершенствования представлен в аналитическом документе «Развитие законодательства и практики реализации государственного социального заказа в Беларуси», Валерий Журавковский, Минск, 2020 <http://actngo.info/wp-content/uploads/2020/04/%D0%9C%D0%BE%D0%BD%D0%B8%D1%82%D0%BE%D1%80%D0%B8%D0%BD%D0%B3-%D0%93%D0%A1%D0%97-2020-04.pdf>



- exclude prohibition to carry out commercial activities from the Law of the Republic of Belarus "On public associations" (article 20);
- exclude from the existing legislation the list of goals, for which NGOs can receive charitable aid, retaining the list of goals, for which charitable aid cannot be received.

### 3. Procedure of social contracts formation and placement

To implement the SC mechanism, it is critical to:

- carry out quantitative studies of the needs of people affected by TB in medical and social services, which can be provided through the SC mechanism, and submit the results of such studies to the local authorities responsible for social contracting;
- NGOs should describe their best practices of providing services to people affected by TB, calculate the costs of such services and present the best practices to the local authorities responsible for social contracting;
- organize knowledge sharing for potential SC customers and implementers in the area of TB based on the experience of SC implementation in the area of HIV.

### 4. Favourable conditions for NGOs and communities

To build the capacity of NGOs and communities, it is important to:

- provide equal opportunities to all public associations in carrying out activities all over the territory of the country by cancelling the division of public associations into local, republican and international through making relevant amendments in the Law of the Republic of Belarus "On public associations";
- abolish administrative responsibility – article 23.88 of the Code of Administrative Offenses – for activities on behalf of non-registered organisations and cancel prohibition for the activities of non-registered associations, deleting relevant provisions from article 7 of the Law of the Republic of Belarus "On public associations";
- increase access of NGOs and communities to up-to-date information on the situation with socially dangerous diseases, including TB.



**For records**





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