



**Regional meeting on capacity building of CSOs to advocate for safe and affordable  
DR-TB treatment in the EECA region**  
*June 18 – 20, 2019, Kyiv, Ukraine*

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**Goal:** To build capacity of civil society activists to advocate for prompt transition to new WHO guidelines to treat DR-TB in the EECA countries and stop the common use of injectable drugs with health-deteriorating side effects on people with DR-TB.

**Objectives:**

- Increase understanding of the principles of the new WHO guidelines on DR-TB for achieving quality people-centered and rights-based TB care;
- To discuss common barriers and possible solutions for the implementation of the WHO new drug-resistant TB treatment guidelines and strengthen TB-HIV collaboration;
- To strengthen and expand advocacy activities of communities and CSOs for an urgent transition from injectables to oral treatment in the region of Eastern Europe and Central Asia.

**Brief overview:**

The regional meeting was organized by the TB Europe Coalition (TBEC) in the frames of the Communities, Rights and Gender Global Fund Strategic Initiative. The meeting aimed to increase the potential of civil society activists to advocate for national health systems in the EECA region to use the new WHO guidelines and limit the widespread use of injected treatments with dangerous side effects which are currently given to people with DR-TB. Alongside the provision of new drugs, it is important that everyone has access to social and psychological support as well as medicines. This is especially important for key population groups at all stages, from access to diagnosis to the treatment itself.

Over the course of three days, 25 participants from Armenia, Azerbaijan, Belarus, Georgia, Kazakhstan, Kyrgyzstan, Moldova, Ukraine and Uzbekistan were able to build their potential to support national programmes in moving to the new WHO guidelines. The participants represented civil-society organizations, and community organizations of people who survived TB and people living with HIV.

Our close partners from leading international organizations attended the meeting. Dr. Medea Gegia from the Technical Support Coordination Unit of the Global TB Programme, World Health Organization, Tsira Chakhaia, Regional Manager for Eastern European and Central Asia countries, Global TB Caucus Secretariat, Svetlana Nicolaescu, Project Coordinator from the PAS Center attended the full event and participated in all the sessions.

Andrey Klepikov, Executive Director of Alliance for Public Health, came to greet the participants at the opening session and Dr. Lucica Ditiu, Executive Director of the Stop TB Partnership send her inspiring video greeting as she could not come due to other commitments.

Sandra Irbe, TB REP 2.0 Portfolio Manager at the Global Fund also joint the Regional Meeting for Day 3.

The meeting was facilitated by Paul Sommerfeld, Co-chair of TBEC; Sergii Filipovich, member of rGLC, WHO European Region, and Member of TBEC Oversight Advisory Committee; Jonathan Stillo, Associate Professor of Anthropology, Wayne State University, and TBEC Board member; Yuliya Chorna, Executive Director of TBEC; Yuliia Kalancha, TBEC Advocacy and Policy Manager, and Daniel Kashnitsky, TBEC Capacity Development Manager, from TBEC Secretariat.

At the regional meeting the participants were able to:

1. Increase their awareness and understanding of the WHO guidelines on MDR-TB treatment;

2. Find out about different tools that civil society can use to monitor side effects from DR-TB treatment, and what they must do to ensure the patient's safety throughout treatment;
3. Learn about international mechanisms that help lower the price of TB medications;
4. Identify effective ways to engage with parliamentarians in the EECA region to help overcome structural barriers;
5. Discuss the experience of Ukraine in introducing the new WHO guidelines and the barriers that arose at various stages and levels during the process;
6. Identify barriers (at the individual, societal, institutional and legal level) in their own countries that might impede the introduction of the WHO guidelines and steps advocates will need to take to overcome these barriers.

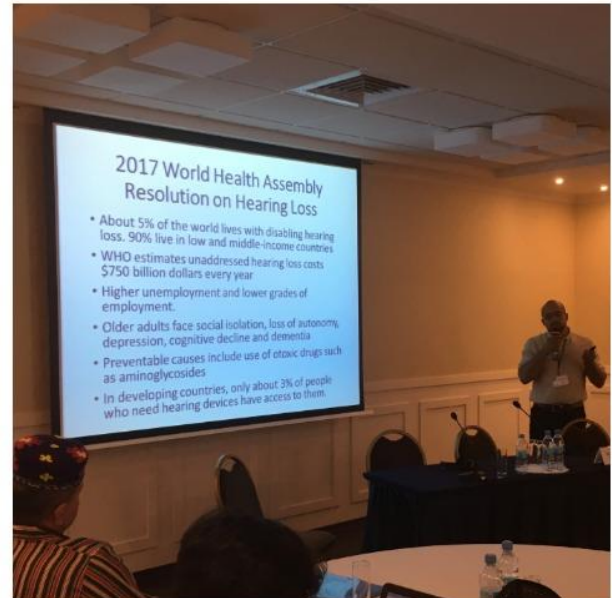
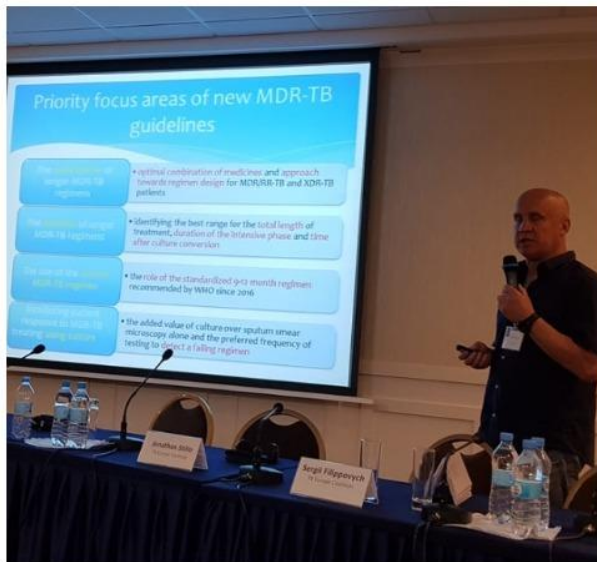
Participants had the opportunity to strengthen their relationships with civil society organizations working in the realm of TB and HIV through group exercises, roleplay activities, and through dialogue with experts. They shared their experiences working to control TB and enforce new strategies for treatment at the national and international level. This allowed everyone to determine the steps needed in each country to make sure that safe treatment is available to everyone in need of it. Finally, through the personal stories from people who have survived TB, participants saw that in addition to new drugs, patients need multifaceted treatment at every stage, from diagnosis, treatment options, psychosocial support, especially for key population groups.



### **Day 1 – Day 2, June 18-19, 2019**

The first day was educational and focused most on building capacity and participants. The first session aimed to ensure participants' understanding of the WHO key guiding documents on transition towards better treatments of drug-resistant TB and was delivered by Sergii Filipovich, member of rGLC, WHO European Region, and Member of TBEC Oversight Advisory Committee. Dr Medea Gegia from the Technical Support Coordination Unit of the Global TB Programme, World Health Organization make an outline of how new WHO DR-TB guidelines were developed and how they are implemented. Challenges associated with implementation of news DR-TB guidelines treatment in EECA were presented in detail by Jonathan Stillo, Associate Professor of Anthropology, Wayne State University, and TBEC Board member.

Organization. This session explained why there is a strong movement to discourage the use of injectables even though a regimen with them is still acceptable. A group exercise was co-facilitated by Paul Sommerfeld and Sergii Filipovich to memorize the most important parts of the new WHO guidelines and translate this document into simple advocacy messages to decision makers from the community perspective.



In the next session participants got introduced into the psychological perspective and challenges of people who undergo DR-TB treatment and their family members, as well as ethical and human right aspects of in DR-TB treatment, such as informed consent.

*“Yesterday I was struggling to recover from multi-drug resistant tuberculosis, wondering how can it be that in this day and age one person and one family has to cope with so much trouble almost entirely on their own”. (Safarali Naimov, Executive Director of Stop TB Partnership association, Tajikistan, MDR-TB survivor).*

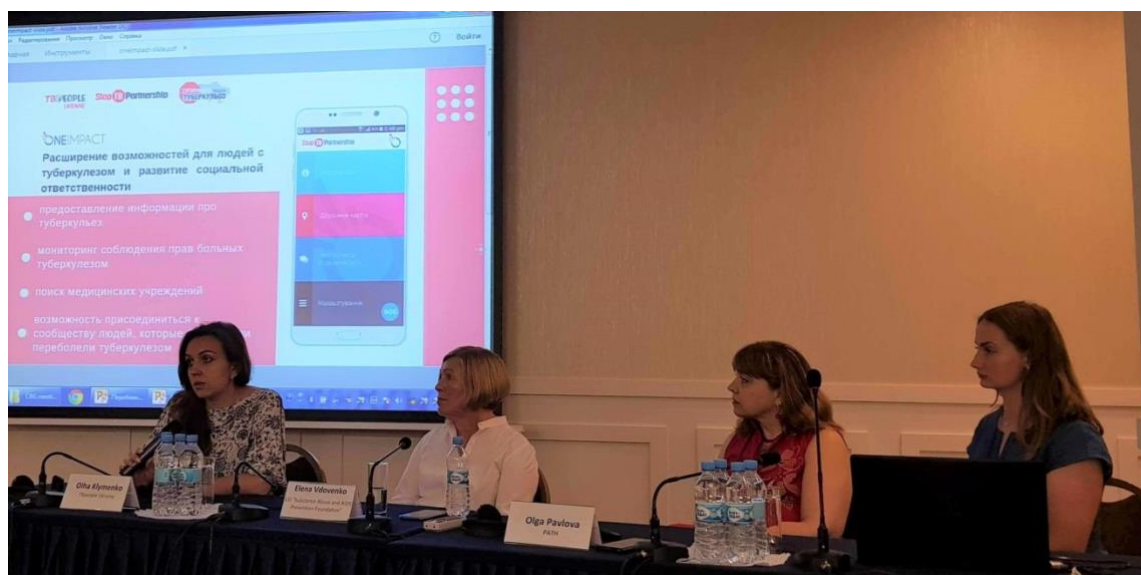
The next session delivered by Jonathan Stillo, Associate Professor of Anthropology, Wayne State University, and TBEC Board member, Ethical and human rights perspectives in DR-TB treatment, reflecting on how the new guidelines impact the social determination of the person's life through the prism of human rights and the linkage with informed consent. Later Johnathan moderated a group exercise that allowed the participants to feel and internalize the ethical issues which people with TB could face and will help to determine solutions.

A special panel was held to discuss barriers on the way to launch of new WHO DR-TB guidelines and the role of civil society to overcome these barriers in Ukraine with the participation of Dr. Iana Terleieva, Head of the TB Treatment Programs of Public Health Center, TB Expert of the Ministry of Health of Ukraine Andrii Skipalskyi, General Director of the Public Health Directorate of MoH, Ukraine, Alberto Dal Poz, Ukraine Advocacy Manager, Médecins Sans Frontières (MSF), Professor Nataliya Nizova, Alternat of Global Fund Board Member from the Constituency of Eastern European and Central Asian countries, Advisor to Vice Prime Minister of Ukraine.



This session gave a specific example how the cooperation of civil society, state officials and expert community allowed to overcome the barriers and register new life-saving drugs in Ukraine.

On Day 2 a very dynamic panel discussion took place to discuss what state mechanisms and civil society tools exist to monitor the side effects of DR-TB treatment and what needs to be done to make patient treatment safer. This session moderated by Yuliia Kalancha, TBEC Advocacy and Policy Manager, gathered three experts: Dr. Olga Pavlova – PATH, Senior program officer in Ukraine and a former NTP manager in Ukraine, Olha Klymenko, Chair of the Board of “TBpeople Ukraine”, Board member of TB Europe Coalition, Elena Vdovenko, Substance Abuse and AIDS Prevention Foundation, psychologist at the patients’ hotline.



Another important session and a group exercise introduced the participants with special advocacy tools that help reduce prices for TB drugs, including strategies and interventions that can be used to break monopolies, including patent oppositions. The group exercise help by Yuliia Kalancha, TBEC Advocacy and Policy Manager and Vladyslav Denysenko, Senior Advocacy Officer, CO “100% LIFE” helped participants develop advocacy steps to reduce prices in their home countries. Within this session Sergii Filipovich, member of rGLC, WHO European Region, and Member of TBEC Oversight Advisory Committee, presented about International mechanisms of advocacy for price reduction of safe drugs to treat MDR-TB.



The concluding session of the second day was a role play Negotiations with decision makers.



### **Developments from the group exercises**

#### *Moderators:*

*Paul Sommerfeld, Co-Chair of the Board, TBEC*

*Daniel Kashnitsky, TBEC Capacity Building Manager*

Participants were asked to divide into three groups and identify different types of barriers providing safer treatment of DR-TB: 1. on the level of individual and the community, 2. on the level of medical institutions; 3. Legal and regulatory barriers. They also had to briefly think of possible solutions, some of which applied to several barriers at a time.

On Day 2 participants were asked to brainstorm ideas for immediate action, mapping partners and possible allies for advocacy. We summarized the group work outcomes below.

#### **Barriers on the level of the individual and the community:**

- fear of side effects,
- no trust to new drugs,
- a belief that injectable drugs are more efficient,
- lack of reliable information within the patient community (selective and insufficient information from the doctors)
- insufficient state funding and weak mechanisms of TB program implementation;
- underestimation of the importance of psychosocial support during TB treatment;
- self-stigma
- being a part of a key population

Possible solutions	Partners
<ul style="list-style-type: none"> <li>- Educating patients and providing information about new drugs by distributing printed materials, creating posters and video materials, as well as groups in social media; mobile applications and cooperation with media people who can make information about TB more accessible;</li> <li>- Creating a standardized package of psychosocial services that should be provided by the state on a regular basis;</li> <li>- Engaging CSOs to organize support groups and peer consultations;</li> <li>- Find local allies who can help to promote allocation of state funds to support patients during treatment with new drugs;</li> <li>- Document cases of people who were badly affected by the injectables;</li> <li>- Document side effects of injectable drugs.</li> </ul>	<ul style="list-style-type: none"> <li>- Country coordination mechanism</li> <li>- TB doctors</li> <li>- NTP</li> <li>- Opinion leaders</li> <li>- People who survived TB</li> <li>- National CSOs</li> </ul>

**Barriers on the level of medical institutions:**

- Human resources: not enough young TB doctors to replace the elder generation;
- Too little capacity building for TB doctors;
- Stigma and discrimination in the medical facilities;
- Heads of TB units are not ready to cooperate with CSOs;
- Excess of power: e.g., forces hospitalization;
- No integration of services: with HIV, harm reduction
- Doctors have too little information on people centered care;
- Little funding; low wages;
- Too remote location of the TB units.

Possible solutions	Partners
<ul style="list-style-type: none"> <li>- Integration of TB services into primary healthcare;</li> <li>- Identify partners to join forces, create a team of NTP, CSOs, international organizations</li> <li>- Engage CCM to voice barriers and find solutions;</li> <li>- Invite international partners who can help draft the required national documents: USAID, CDC, MSF.</li> </ul>	<ul style="list-style-type: none"> <li>- NTP</li> <li>- National CSOs</li> <li>- International organizations and projects</li> <li>- TBEC</li> <li>- Country coordination mechanism</li> <li>- USAID, CDC and other technical agencies</li> </ul>

**Barriers on the level of legal and regulatory barriers:**

- access to new drugs registration;
- national procurement rules do not allow to purchase new drugs,



- no import waivers;
- lack of use of TRIPS flexibility and compulsory licensing;
- local authorities are not allowed to purchase drugs, only MoH;
- procurement of services that health system cannot provide;
- lack of multisectoral approach: e.g., OST is not available in TB units and other limitations

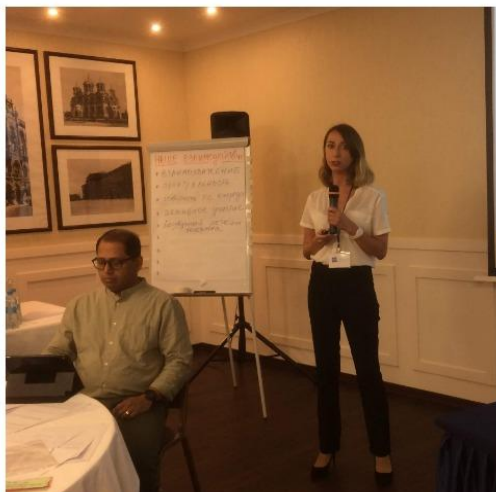
Possible solutions	Partners
<ul style="list-style-type: none"> <li>- conduct legal environment assessment;</li> <li>- register updates in Essential Medicines List (EMA) on the national level;</li> <li>- recognition by Stringent Regulatory Authorities (SRA)</li> <li>- advocate for political decisions: friendlier interpretation of existing laws and changing legislation;</li> <li>- adopt standard of services;</li> <li>- look for best practices in the region.</li> </ul>	<ul style="list-style-type: none"> <li>- NTP</li> <li>- National MPs</li> <li>- International organizations and projects</li> <li>- Country coordination mechanism</li> <li>- TB Service</li> </ul>

In this group exercise, participants had to brainstorm ideas for immediate action related to one of the solutions identified the day before. After that, they had to identify partners and map potential allies for advocacy action. Participants worked in the same groups as on Day 1.

### Day 3, June 18-19, 2019





On Day 3 the last expert panel discussion was dedicated to how civil society can leverage political support to overcome barriers in access to safer treatment of DR-TB with a particular focus on the potential support on behalf of parliamentarians.





Zahedul Islam, Director of Treatment, Procurement and Supply Management Department, Alliance for Public Health made a presentation on the TB Parliamentary Platform in Ukraine and told about the best practices for developing collaboration between members of parliament and the civil society in the WHO European Region. Alesia Matusевич, Assistant to MP Mr. Serhiy Kiral, member of the Coordination Committee of IFA Parliamentary platform for Combating TB complemented the story about the Ukrainian cooperation experience with MPs by giving specific tips for successful engagement between the civil society and parliamentarians. And a brilliant example of cooperation and advocacy from Inna Ivanenko, Executive Director, CF “Patients of Ukraine” as well as from a strong TB advocate from Azerbaijan - Elchin Mukhtarli, Director of NGO “Saglamliga Khidmat” from Baku.



The group discussion that followed was dedicated to development of key messages to members of parliament. As this session preceded the Eastern Europe and Central Asia TB Summit civil society participants had an opportunity to attend the first session of the TB Summit and have a live discussion with real parliamentarians from Georgia, Ukraine, and Tajikistan.

### Key messages for parliamentarians to ask them for engagement and support

	<b>Moldova</b>	help solve human resource issue in national TB service
	<b>Kazakhstan</b>	promote social contracting at the local level
	<b>Belarus</b>	bring up the identified barriers in TB service (CCM group has recently conducted a study of existing barriers) to discuss them at the parliament hearings
	<b>Kyrgyzstan</b>	Continuous access to TB care for international migrants from Kyrgyzstan in receiving countries; Initiate development of a transition plan to national funding for TB care; Initiate fraud investigations in TB care; Voice TB-related issues in national media to bring down stigma and discrimination of people with TB.

	<b>Armenia</b>	Facilitate access of CSOs to TB hospitals; Initiate development of a national plan to include CSOs to provision of psychosocial care;
	<b>Georgia</b>	Mechanisms of transition to national funding for national CSOs and funding available to support services during transition
	<b>Tajikistan</b>	Initiate creation of the national strategic plan where funding for NGOs would be available; Invite parliamentarians to local TB events – in the localities where they come from
	<b>Ukraine</b>	Ensure state funding for CSOs working in TB care is available shortly



### Participants' commitments

At the end of Day 3 participants were asked to share their commitments – what they would do when they return to their home country to promote the use of life saving TB drugs.

#### Azerbaijan:

- Meeting of TB Europe Coalition members to give them feedback on the Regional meeting in Kyiv;
- Discuss at the meeting who might be the national champion for introducing new drugs and regimens;
- The Champion will assist the Vice-President of Association who has the power to influence decision-makers.

#### Uzbekistan:

- Inform community of the regional meeting in Kyiv;
- Inform TB service about new drugs and new recommended treatment regimens and see how they fit with the National TB Program;

- I'll go back to learning the procedures of licensing and registration of new medicines in Uzbekistan.

### **Tajikistan:**

- Inform STOP TB Partnership Association staff about the issue of access to new drugs;
- Share full info via google list serve;
- Make a post via social media;
- Write an article for a newspaper for general population.

### **Kyrgyzstan:**

- Conduct meeting with colleagues to inspire them with new knowledge from the Kyiv;
- Check the national list of drugs and treatment protocols, and collect information how to register new medicines (contact the department of registration);
- Evaluate legal documents in standards of TB care as well as legal provisions that regulate service provision on the local level.

### **Moldova**

- inform the participants of the key populations platform about the regional meeting results;
- initiate national platform meeting to define barriers to introduce new life saving drugs;
- together with the platform start developing action plan to introduce new life saving drugs in Moldova;
- define advocacy target and start implementing the plan;
- support patient organizations and help them build capacity to support their greater role in the implementation of advocacy plan.

### **Kazakhstan:**

- inform activists about the meeting;
- develop and promote mobile application with relevant information;
- meetings regarding allocation of funding;
- meetings with TB service.

### **Belarus:**

- make list of specialists who can be a part of the CCM group on social contracting; as a national coordinator for this group I'll write the requirements for experts
- we'll inform wider audience about the problems identified on Defeat TB Together Facebook page;
- I'll complete the analysis of questionnaires on the CCM survey.

### **Ukraine:**

- Advocacy of approval by MoH of the new MDR-TB treatment protocol;
- Initiate discussion of reform of TB service provision;
- Monitor transition plan to national funding.

### **Armenia:**

- meeting with NTP manager – ask him how many people undergo treatment with new drugs.
- Conduct independent interviews with patients who undergo treatment now: to understand what fears and concerns they have and what can support them in treatment;

- Develop support program for patients who get new treatment;
- I'll inform the public more about what my organization does.

**Georgia:**

- I'll share my new knowledge with colleagues and activists about the new knowledge I acquired.

***According to evaluation results, achieved knowledge and skill mentioned by participants:***

The most common practical skill was

- "negotiations with pharma and ministry" and
- "negotiation on price reduction, patent oppositions".

Other knowledge and skills that the participants mentioned include:

- parliamentary platform as a leverage of influence on public opinion;
- new WHO recommended schemes of treatment;
- technical assistance of GF to countries implementing GF grants;
- recommendations on ambulatory treatment;
- integration of services;
- sharing best practices of activism;



**Annexes:**

1. Program \_ <https://drive.google.com/drive/u/1/folders/1CX2-niz6Pajjfw902OK9ucwemBMgkD6>
2. Presentations\_ <https://drive.google.com/drive/u/1/folders/11yqqFacVQgfr4AqrJ9h3bq572UlyVlvY>