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Tuberculosis Regional Eastern European and Central Asian Project (TB-REP) civil society involvement and update dialogue

**Copenhagen, Denmark
7–8 March 2017**

Meeting report

ABSTRACT

This Tuberculosis Regional Eastern European and Central Asian Project (TB-REP) civil society and partners' update dialogue was organized by the WHO Regional Office for Europe and the StopTB Partnership, in collaboration with the Centre for Health Policies and Studies, TB Europe Coalition and the Ukraine Health Alliance. The aims were for civil society organization representatives from the 11 TB-REP countries to discuss common approaches to advocacy for appropriate TB models of care, describe their experiences and identify key barriers to people-centred care, and report on implementation of their grant and plans for the second year of TB-REP. Representatives from partner organizations also gave presentations and led discussions on synergistic activities. The 11 TB-REP countries are Armenia, Azerbaijan, Belarus, Georgia, Kazakhstan, Kyrgyzstan, the Republic of Moldova, Tajikistan, Turkmenistan, Ukraine and Uzbekistan.

Keywords

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CONTENTS

Page

Acronyms and abbreviations.....	iv
Executive summary	v
Welcome	1
Update on TB-REP implementation	2
Panel discussion: update on TB-REP blueprint development and guiding principles of people-centred TB models of care	3
Regional TB-REP advocacy strategy and strategic directions.....	4
Updates from partners on regional proposals and TB-REP-relevant initiatives	6
Panel discussion: linkages and synergies between TB-REP and other regional work	7
Country advocacy strategies.....	7
Panel discussion: challenges and lessons learnt	9
Panel discussion: how TB-REP can contribute to addressing the challenge of the human-resource situation.....	10
Panel discussion: how TB-REP can improve government acceptance for policy-change	11
Cross-linkages between TB-REP components	13
Breakout groups: the way forward, focusing on tangible and feasible outputs	14
Concluding remarks.....	15
Annex 1. Programme	16
Annex 2. Participants	19

Acronyms and abbreviations

CSO	civil society organization
DOTS	directly observed treatment, short-course
DR-TB	drug-resistant tuberculosis
ECUO	East Europe and Central Asia Union of People Living with HIV
KAP	knowledge, attitude and practice (study)
NGO	nongovernmental organization
NTP	national tuberculosis programme
TB	tuberculosis
TB-REP	Tuberculosis Regional Eastern European and Central Asian Project
UNAIDS	Joint United Nations Programme on HIV/AIDS

Executive summary

The WHO European Region has seen the highest annual decline (5.2%) for tuberculosis (TB) over the past decade, but TB remains an important threat to public health and is increasingly becoming more difficult and expensive to treat. The burden of disease in the Region varies from very low incidence levels of less than 10 per 100 000 population to rates that exceed 100 per 100 000. The Region represents only 5% of the global TB burden but reports the highest rates of drug-resistant TB (DR-TB). Prevention and successful treatment of DR-TB are key priorities, and the latest regional reports of DR-TB among new (18.4 %) and previously treated cases (46.2%) in 2014 are of great concern.

The high disease burden and the emergence of DR-TB are partly attributed to inappropriate and poor health-care delivery, but other important factors, such as dissolution of the Soviet Union, the global financial crisis and mass migrations, are affecting countries' ability to find sustainable health-financing mechanisms. In addition, the fragility of national health systems is increasing as countries transition from external donor funding as their economies improve.

The Tuberculosis Regional Eastern European and Central Asian Project (TB-REP) was launched in January 2016 as a three-year project with financial support from the Global Fund. Its overarching goals are to stop the spread of TB and DR-TB and improve treatment outcomes in 11 target countries by increasing political commitment and implementation of people-centred TB models of care. A key project activity is to develop guiding principles that can be adapted and implemented in project countries with support from nationally assigned civil society organizations (CSOs) that advocate for quality services and ensure the voices of those who are most vulnerable are heard.

A TB-REP civil society involvement and update dialogue was held in Copenhagen, Denmark, on 7–8 March 2017 to:

- present TB-REP people-centred models of TB care and guiding principles to CSOs and partners;
- present the essential elements of CSO national TB-REP advocacy strategies;
- present and discuss cross-linkages between TB-REP components, with a focus on how they could be further improved;
- present and discuss case studies of CSO advocacy work to advance progress on models of care and identify lessons for TB-REP stakeholders; and
- discuss how synergistic non-TB-REP partner activities and interventions could be capitalized.

Presentations and discussions were in English and Russian with simultaneous translation throughout the two days of the meeting. Annex 1 presents the programme of the meeting, and Annex 2 lists participants.

Welcome

Dr Masoud Dara (Coordinator, Communicable Diseases and Programme Manager, Joint TB, HIV and Hepatitis Programme, WHO Regional Office for Europe) welcomed all Tuberculosis Regional Eastern European and Central Asian Project (TB-REP) members and other participants and asked all to share their expectations from the meeting. He encouraged participants to have open dialogue to share experiences and achievements of the past year and strengthen collaboration with other programmes.

Setting the scene

Dr Nedret Emiroglu (Director, Health Emergencies and Communicable Diseases, WHO Regional Office for Europe) opened the panel discussion by affirming the good progress toward targets set in the TB action plan for 2016–2020, but warned that disease-specific programmes can only deliver up to a point: structural barriers need to be overcome if TB is finally to be eliminated in the Region. Strong collaboration with the Division of Health Systems and Public Health is leading the expansion of systematic and integrated approaches in the Region, and full engagement of civil society organizations (CSOs) ensures the best people-centred models of care are implemented in countries. Although the regional TB programme has been doing much substantive work, health emergencies and other programmes (such as hepatitis and HIV) are attracting more funding. She concluded by placing high value on the TB-REP project and looked forward to concrete actions for the benefit of all countries in the Region.

Dr Hans Kluge (Director, Health Systems and Public Health, WHO Regional Office for Europe) used his professional experiences to demonstrate how strengthened health systems and good TB control are interconnected. He stressed that developing holistic approaches to improve, maintain and restore health are values deeply embedded in the Tallinn Charter. New case-management approaches that can overcome obstacles and offer enablers need to be developed, while recognizing that “one size does not fit all”. He noted the challenges posed by current health-financing methods that are determined by the volume of patients going through the system. He also stressed the role of CSOs in ensuring countries deliver people-centred care and thanked participants and representatives of the Global Fund and StopTB Partnership for their support and continuing excellent collaboration.

Dr Viorel Soltan (Director, Centre for Health Policies and Studies) compared health-care delivery systems for TB and HIV in the Region and cited the high concentration of TB specialists to HIV specialists in the Republic of Moldova as an example of persistently top-heavy TB services in some countries. He noted that the Global Fund was the first to move towards systems for health, as opposed to health systems, thereby putting patients at the centre of care, but progress to final eradication of TB depends on taking full advantage and making the best use of new developments and technologies.

Dr Uldis Mitenbergs (Fund Portfolio Manager, Global Fund) described Global Fund financing of the TB-REP as another effort towards developing sustainable and resilient health systems in the 11 countries in the project. He cautioned that to be effective agents for change in their communities, CSOs need to be specific in their advocacy messages and set clear expectations for people-centred care. A blueprint that describes in detail this new people-centred approach is being developed and would be a useful tool for CSOs in their advocacy efforts.

Ms Fanny Voitzwinkler (Coordinator, TB Europe Coalition) asked what can be done differently, as some members may feel frustrated by the heavy influence of medical professional groups in this field. She suggested that CSOs must be viewed as a complementary resource that can bring patients and providers closer together. CSO members need to be able to understand new and complex issues, yet often do not get sufficient financial support to enable them to acquire new skills. While CSOs need to build a movement to advocate for quality care in the Region, they face a practical difficulty in explaining the concept of people-centred care in countries where the phrase does not translate well in Russian.

Thirteen years to ending TB – can we get there, and how?

Dr Lucica Ditiu (Executive Director, StopTB Partnership)

The ambitious targets set in the Sustainable Development Goals – to end the global TB epidemic by 2030 by reducing mortality by 90% and incidence by 80% – were largely driven by the declines observed in the HIV epidemic, and it is unlikely that they will be met.

Current global trends show that progress remains slow, although the WHO European Region has seen the greatest reduction of notification rates across all regions (by 5% per year since 2005). In the context of the first ever United Nations high-level meeting on TB in 2018, Dr Ditiu proposed that interim targets need to be in place by 2020 to close the gap of the millions of cases that remain undiagnosed and untreated in many parts of the world.

Ending the TB epidemic is proving to be very difficult, despite continuous financial support from the Global Fund. The inherent nature of the disease has so far precluded the discovery of an effective vaccine, and the need for a prolonged course of treatment with many drugs remains a problem. Different approaches that involve communities are needed, as “using the same people and the same strategies will not work”. Dr Ditiu nevertheless cautioned that continued funding of advocacy activities depends on demonstrable results. CSOs must earn the trust of their national TB programme (NTP) counterparts and communities and serve as a portal to facilitate better communication between patients and health-care providers.

Update on TB-REP implementation

Dr Stela Bivol (Director, Centre for Health Policies and Studies) and Ms Yuliya Chorna (Project Manager, “Alliance for Public Health”) presented a brief update on work, progress and achievements during the first year of the project.

TB-REP CSOs are a very dynamic group and are laying the ground for conducting structural assessments and developing national advocacy strategies in several countries. CSOs cannot work in isolation: they need to engage effectively with other stakeholders and show they can bring a practical dimension to changes occurring in health systems. Support and recognition given through collaboration with WHO is increasing the value of CSOs in the Region.

TB-REP’s goal is to reduce the burden of TB and drug-resistant TB (DR-TB) in the 11 eastern European and central Asian target countries by facilitating the implementation of evidence-based and financially sustainable people-centred TB services. This will be achieved through increasing political commitment to health-system strengthening, efficient resource allocation and regional collaboration. Extensive activities in the past year included meetings with national focal points, working groups and international partners, high-level advocacy events in countries, a regional

intercountry event hosted by WHO in Copenhagen, Denmark, and a training programme on strengthening health systems for improved TB prevention and care at a WHO collaborating centre.

Groups are currently engaged in performing situational analysis and conducting interviews with patients and providers to identify barriers to care and are also developing information campaigns. TB-REP has managed to gain highly visibility in the Region and has established effective working relationships with country coordinating groups and international agencies such as the Global TB Caucus, the East Europe and Central Asia Union of People Living with HIV (ECUO) and the Eurasian Harm-reduction Network. Work over the next two years will focus on developing tailored country roadmaps for health-system strengthening and will include technical consultations, technical assistance missions and impact analyses. Preliminary data on performance based on the two key indicators (hospital admission rates and length of stay) show that progress is slow, but it is expected that this will pick up in the second and third years of the project.

Points raised during a brief discussion included:

- managing the expectations of patients and communities may be challenging – developing materials and conducting surveys takes time, but people often expect quick results;
- some practitioners in the field may feel isolated, as other stakeholders are often slow to respond;
- hospitals offer employment to a wide range of people and may be perceived positively by the community in their catchment areas; and
- health professionals may actively resist implementing new outpatient-based services, as they fear loss of status and financial security – the blueprint should make the switch easier by showing providers that they are part of the solution and can be reintegrated in the new system.

Panel discussion: update on TB-REP blueprint development and guiding principles of people-centred TB models of care

Key points from the interactions by participants were as follows.

Key purpose of the blueprint

This is an innovative approach to public health that could assist countries in choosing and developing new health systems and financing models. The CSO role in the blueprint evolved naturally, and it is now clear that CSOs need to be an integral part of health-system transformations in the Region, shifting from “what?” to “how?” modes of thinking.

The blueprint is a collaboration involving the London School of Hygiene and Tropical Medicine, London School of Economics, the European Respiratory Society, PATH, WHO and technical experts. It is a comprehensive instrument with key elements (outpatient care, financing mechanisms, developing human resources) and is data-driven to support governments to tailor their policy options. The blueprint also serves as an advocacy tool that CSOs can use, but they must be fully aware of the harsh realities of finding sustainable funding as countries transition from Global Fund support.

Expectations from the blueprint and the role of CSOs

People-centred care needs to be clearly defined and explained. The blueprint should provide succinct and practical step-by-step actions that inform policy-makers, communities, patients and their families about the basic elements of people-centred care. CSOs have already contributed by conducting questionnaires and focus groups in the field and can investigate further the synergies between medical care and social contracting. CSOs will be invited to attend the annual NTP managers' meeting hosted by WHO.

Barriers

- Many TB specialists are unenthusiastic about ambulatory care and remain deeply grounded in their belief that patients are potentially infectious unless they have a smear-negative result. Lay understanding is in turn influenced by these authority figures. CSOs must be able to provide and explain the scientific proof to convince patients and communities that this model of care poses no risk of transmission to the community. They also need to advocate for the rights of patients.
- CSOs face several barriers. Lack of funding for operational activities by CSOs is a major hurdle, as many countries do not fund CSOs and Global Fund rules do not allow funds to be used for salaries. Intangible CSO activity outputs, such as offering support and changing attitudes, cannot be measured and reported as performance indicators.
- Post-Soviet methods that determine compensation and financing based on hospital bed occupancy persist in countries. Building on old models is very difficult and is more likely to fail, but at the same time the needs of certain high-risk groups for hospital care must not be ignored.
- TB programmes are embedded in old practices and are not oriented towards patients' needs. This contrasts with more recent HIV programmes, which are more responsive to the needs of their clients.

Opportunities

- TB-REP country focal points are highly placed officials and CSOs can actively use these counterparts as their platform for advocacy.
- CSOs should push at all levels to make sure that the "money follows the patient".
- Policy change must avoid falling into the trap of dismantling services without providing suitable and acceptable alternatives.
- Opportunities exist to collate best practices, demonstrate the effectiveness of pilot projects that can be replicated on a larger scale, and develop evidence-based algorithms that can be used to support clinical decision-making.
- CSOs should collaborate and share resources with other programmes, such as HIV and hepatitis.
- The need for capacity-building of CSO members calls for the course on health system financing at the WHO collaborating centre in Barcelona, Spain, to be made more accessible.

Regional TB-REP advocacy strategy and strategic directions

Ms Fanny Voitzwinkler (Coordinator, TB Europe Coalition) and Ms Yuliya Chorna (Project Manager, "Alliance for Health") presented the strategy and directions for the two organizations that have overall responsibility for supporting civil society in TB-REP.

TB Europe Coalition

Civil society is the driving force behind people-centred TB care. This recognition provides the base for all TB Europe Coalition activities for 2017–2020, which cover sustainable financing and mobilizing domestic resources, human rights, and advocating for research on new tools, drugs and vaccines.

The TB-REP regional advocacy strategy is defined by four elements: coordination, community, sustainability and political commitment. TB-REP advocacy work should be coordinated, link confidently with professional and technical experts, and facilitate active community engagement, including family members, religious and political leaders, and online movements. The sustainability of activities beyond the life of the grant must be addressed, and sharing common resources with other projects and moving away from silo approaches are possible solutions. Working with European Union partners and WHO will create safety nets and strengthen political ties to ensure continued support.

A recent project in Belarus provides an example of positive contributions from CSO work, where it was found that 25% of the TB budget was used for involuntary isolation and another 25% for mass screening. Enforced isolation has consequences for parental rights and employment prospects in the country and is an important barrier to seeking early medical attention.

“Alliance for Health”

The new people-centred TB care model is a comprehensive package that should cover the assessed needs of patients. The main objectives are to cure patients and reduce hospitalization costs, but it should also consider the needs of patients who often find themselves isolated, unemployed and unable to lead a normal life. Shifting totally to ambulatory care services is not sufficient, as hospital care may be more appropriate in instances where financial and social support to help patients cope are lacking.

Countries are adapting and experimenting with new services; a pilot project using video-observed therapy is an example. Some CSOs are moving towards integrating with HIV programmes, but more coordination is necessary to link the different agencies. CSOs should communicate with health-care professionals and address important issues, such as the duration of infectivity and maintaining care quality. A project in the Republic of Moldova was cited as a good-practice example of CSO services that can be adapted by other countries.

Discussion

During a brief discussion, questions were asked about how the project is evaluated and how its different parts align. Responses included the following.

- The evaluation of the first year of the project is data-driven and reports on key performance indicators. Evaluation of missions in countries is multi-layered and is more subjective, but the information collected and reported has been received extremely well by WHO.
- WHO and the StopTB Partnership have discussed how to integrate elements of the project and a situational analysis that maps and identifies which countries need more support is under way. Activities in the second year will be tailored to specific needs in countries. High-level meetings between WHO and ministries of health will be held to discuss areas of further cooperation, and it is expected that CSOs will be involved.

Updates from partners on regional proposals and TB-REP-relevant initiatives

StopTB Partnership

Mr Gregory Paton (Strategy and Advocacy Officer) described the four high-level events in 2017 as unique opportunities to gain new audiences and new partners. A communications project launched as part of World TB Day activities provides an extensive set of communications and social media products that can be downloaded by advocacy groups.¹

The Partnership is pushing hard to put TB on the antimicrobial resistance agenda: this has been given high priority by Germany, the host of the G20 Sherpas meeting in March and the subsequent G20 summit in May. The Partnership is also leading efforts to put pressure on WHO to include TB in the recently published WHO global priority list of antibiotic-resistant bacteria.² The 2015 out-of-step report³ is currently being updated and a social media campaign has been launched to encourage countries to update their policies by World TB Day 2018; 10 high-burden countries from the Region are included.

The Partnership is also pushing for a stronger role in the global ministerial conference in Moscow, the Russian Federation, as the resultant Moscow Declaration will feed into the United Nations high-level meeting on TB, which is the highest political meeting ever to be held in support of TB. An ambitious target of reaching 10 million people on treatment by 2020 is being proposed for the high-level United Nations meeting.

Global TB Caucus

Mr Matthew Oliver (Head of the Secretariat) described the Global TB Caucus as an international network of members of parliament spread over 100 countries who are committed to advance and support TB control efforts.

The long-term objective is to link local members of parliament with civil society groups and forge strong and effective collaboration across all levels of the community. Members of parliament are well positioned to influence policy- and decision-making at the highest levels and can be effective advocates for change and action. The Global TB Caucus has strong collaborations with CSOs in the Region and has direct links to the upcoming G20 summit and the United Nations high-level meeting on TB in 2018.

¹ World TB Day [website]. Geneva: StopTB Partnership; 2017 (http://www.stoptb.org/events/world_tb_day/2017/, accessed 17 April 2017).

² Global priority list of antibiotic-resistant bacteria to guide research, discovery, and development of new antibiotics. Geneva: World Health Organization; 2017 (<http://www.who.int/medicines/publications/global-priority-list-antibiotic-resistant-bacteria/en/>, accessed 17 April 2017).

³ Out of step 2015. TB policies in 24 countries. Geneva: Médecins Sans Frontières, StopTB Partnership; 2015 (http://www.doctorswithoutborders.org/sites/usa/files/tb_report_out_of_step_eng_2015.pdf, accessed 17 April 2017).

ECUO

Mr Vladimir Zhovryak (President) introduced the work of ECUO in Ukraine as it seeks to ensure equal opportunities for people living with HIV. He claimed that a special advocacy project for HIV control taken forward in collaboration with TB People and the TB Europe Coalition has saved many lives. There is great willingness to include TB with HIV prevention activities in a unified approach that would bring together WHO, the “Alliance for Health” and the Joint United Nations Programme on HIV/AIDS (UNAIDS) as partners. TB and HIV programmes share many common factors, although the mode of transmission is markedly different. A regional consultation in seven countries has reviewed barriers to HIV care and identified gaps; ECUO is open to more collaboration with TB-REP on similar projects.

Panel discussion: linkages and synergies between TB-REP and other regional work

Key points from the interactions by participants were as follows.

Experiences and methods for networking with local politicians

The level of commitment of elected officials is variable, and forming connections can be very difficult. Members of parliament want to contribute to their local communities, but some may harbour the misconception that a medical background is necessary. Elected officials often do not communicate with NTPs, who in turn tend to be wary of politicians. Elected officials may be regarded as temporary due to high turnover and failure to get re-elected. Working with CSOs can increase public appeal for elected officials, but stigma may have the opposite effect.

The United Nations high-level meeting on TB in 2018

The meeting presents a huge opportunity for the global TB community. CSOs need to push for ambitious targets and a strong political declaration to consolidate global TB efforts. The StopTB Partnership is taking a leading role, undertaking a comprehensive global consultation of CSOs in preparation for the meeting. The lack of sufficient resources for more extensive networking and meetings is regrettable: CSOs must be fully organized and have their priorities set well in advance so their demands feature in the final declaration.

Country advocacy strategies

Representatives from five countries described their work and observations.

Armenia

Ms Anahit Harutyunyan, Project Coordinator, “Positive People Armenian Network”

The network originally focused on HIV/AIDS and has only recently included TB in its area of interest. In-depth interviews with 20 patients and doctors on attitudes towards TB ambulatory services revealed that stigma and fear of discrimination are common. Patients prefer to travel rather than use rural health centres, and young women are concerned about their marriage prospects.

The need for isolation to avoid transmission is generally accepted. Training courses were held in 30 rural villages and 600 people attended, but the stigma persists. Nongovernmental

organizations (NGOs) lack enthusiasm to work in TB, and only one CSO (“TB AND ME”, which is supported by Médecins Sans Frontières funding) is active in TB.

Capacity-building and more funding support to attract and advance advocacy activities are necessary. Combining TB and HIV activities and stronger interaction with members of parliament are possible solutions. Patients often stop treatment and migrate to the Russian Federation for work, and this issue needs to be addressed. Possibilities for World TB Day 2017 that are culturally acceptable are still on the table.

Azerbaijan

Mr Mukhtarli Elchin, Director of NGO “Saglamliga Khidmat”, civil society partner for the TB Europe Coalition, and member of country coordinating mechanism

A professional consultancy group was commissioned to conduct a knowledge, attitude and practice (KAP) study among health-care workers and patients to identify the needs and barriers to transitioning to outpatient care in Azerbaijan. Results have not yet been published, but Mr Elchin reported some observations from respondents. These included:

- patients think treatment in hospital is better or safer because of fear of adverse effects and transmitting the disease to their family;
- local primary health-care centres do not have enough knowledge of the disease; and
- medical treatment without social support is not enough.

TB advocacy in the country is gaining ground, and the collaboration with TB-REP and the TB-REP country focal point is having a catalytic effect on building strong links at higher levels of government. Recent activities of note include running training and conferences with the TB Europe Coalition, exploring and piloting new social insurance and financing methods, and producing a one-minute video promoting TB outpatient care.

Belarus

Ms Natallia Kryshatafovich, republican public association “Defeat Tuberculosis Together” and Project Manager, “Outpatient TB Care Ensures Time for Us, Money for the Country and Health for Everyone”

A structural analysis of TB services in the country reveals that the outpatient care model is not uniformly available, but that good examples of treatment centres in rural areas exist, with some also deploying home treatment units and providing social and financial support.

A questionnaire was used to elicit the opinions of patients and health-care workers, generating interesting observations. Doctors believed strongly that the adequacy of treatment was important, and were alarmed that extensively drug-resistant TB patients were put on a waiting list for treatment. Patients and health-care workers were concerned about the long duration of treatment and fear of drug toxicity. Loss of employment also featured: it was then linked to alcohol abuse and subsequent poor adherence to treatment (the high rate of alcohol abuse is a big challenge for this service model). The WHO country office has shown interest in a similar survey being conducted on a larger scale.

Ms Kryshatafovich expressed her personal concern about the difficulties of registering new drugs in the country and hoped this issue would be on the agenda of the Moscow global ministerial conference at the end of the year.

Georgia

Mr Nikoloz Mirzashvili, Board Member of the Georgia Patients' Union and Consultant at the Georgia Family Medicine Association

Georgia has a high burden of DR-TB cases and poor treatment outcomes (41% success rate in the 2013 cohort). Financing mechanisms still encourage long hospital stays for all cases of TB, and outpatient directly observed treatment, short-course (DOTS) centres do not have sufficient resources to deliver people-centred care. Although many patients prefer not to be hospitalized, they find the daily travel to the DOTS centre is a major setback: video-observed therapy is now being piloted with 27 subjects.

Stereotypes still prevail, and patients think that hospital care is superior to outpatient care. Stigma in the community and among health-care workers is very common. A special group has been established to strengthen TB care in the community – the group includes the deputy minister of health, demonstrating the political commitment to controlling TB in the country.

Tajikistan

Mr Abdusamad Latifov, Assistant Manager of projects on TB, StopTB Partnership, hosted by Young Generation of Tajikistan

A qualitative survey was conducted in 2016 to review outpatient TB treatment services among 400 patients, family members, health-care workers and community members in four pilot districts. The study revealed that 90% of patients and family members preferred ambulatory care at a primary health-care centre due to lower travel costs and fear of unfamiliar and unfavourable hospital conditions. Those preferring hospital care cited constant attention by medical staff, fear of side-effects and regimes with injectable drugs. Only 25% of doctors preferred this model, and 55% of primary health-care nurses and the general community chose ambulatory care.

Second-line drugs and rapid diagnostic tools are readily available in the country. Mr Latifov suggested that the two greatest challenges are poor case-finding and poor treatment outcomes, linked to lack of awareness of TB, low compliance, poor nutrition, significant adverse effects and poverty. New community approaches are being tested to raise awareness, assure quality services and support patients; these include many partners, such as local imams, religious-based charities, a wide range of government departments, patient support groups and even private entrepreneurs, who are funding pilot job centres for patients and ex-patients. Reference was made to “iMonitor”, a new data-driven community-service quality-monitoring tool that is being pilot-tested in conjunction with the StopTB Partnership.

Panel discussion: challenges and lessons learnt

Key points from the interactions by participants were as follows.

Access to second-line drugs

Availability of second-line drugs is restricted in some countries because of regulation and registration issues. Some have taken advantage of a legislative window for drugs covered by Global Fund grants. The main obstacles are the very long registration process and lack of interest among local providers (who have to initiate the registration process) because of poor profits and

small markets. Strict pharmacovigilance standards and lack of translated guidelines is also slowing centralized drug registration and procurement.

Reporting back to the Global Fund

TB-REP members are engaged in innovative work, but the project will be assessed by the Global Fund (the grantee) against clearly defined and tangible key performance indicators. It was suggested that other appropriate performance indicators be considered in the next allocation round. Organizations become more active as they gain more experience, but impact is not easy to measure, or takes a long time. The grant is shared among 11 countries and the funds available do not cover much work. Building a good reputation with the Global Fund and delivering good results are important factors in continuing the relationship.

Managing change

Change may be constrained by elements within TB health services. Not all professionals working at primary health-care level have sufficient training to deal with complex drug regimens and adverse effects, and some CSOs may be more knowledgeable on the needs of patients. Regulations in some countries make it unlawful not to isolate smear-positive patients, even if they are on treatment. Offering incentives to health-care workers may be useful, but will not achieve much unless strong CSOs follow up on quality and performance. CSOs must build good relationships with NTP managers, and visible political backing lends higher authority and influence. Some have managed successfully to involve the private sector, local leaders and popular figures.

Panel discussion: how TB-REP can contribute to addressing the challenge of the human-resource situation

Key points from the interactions by participants were as follows.

Make health-care workers part of the solution

Overcoming resistance in the medical profession is key. Retraining and assurances of job security, as well as rewarding good outcomes, need to be supported at administrative and academic levels. TB-REP can advance these efforts by openly communicating and promoting positive attitudes and beliefs among health-care workers at all levels.

Educate and inform communities

Fear of the risk of transmission is a constant argument for prolonged hospitalization. Scientific evidence on the low risk of transmission to the community and the high risk of nosocomial spread must be clearly explained and confidently communicated to communities and local leaders. Collaborations with international and well recognized organizations can be useful in reinforcing the validity of these messages at higher levels.

Reduce stigma at all levels

Negative attitudes towards TB persist in the community and even among CSOs in the Region. Patients who are not sent for isolation also suffer feelings of guilt. Goodwill ambassadors (such as sports stars, popular singers and other performers) and mass TV campaigns would help reduce stigma. Messages could explain the common symptoms of TB, that it is not genetic, and that TB can be cured. Psychological support services also need to be part of people-centred care.

Increase funding for TB advocacy

Some countries have tried to introduce social contracts for TB work, but the response remains poor. People living with HIV are easier to engage in advocacy work and patient support. The Global Fund needs to reconsider rules that allow funds to be used only for activities and not to pay salaries.

Increase the demand for people-centred care

Patients and their families must feel confident that the total package of care delivered at primary health-care centres is equivalent to what they would receive in hospital. Poverty and poor nutrition are common risk factors and many affected families face catastrophic financial losses. CSOs are uniquely placed to identify and promote the type of enablers that work best for patients – food parcels, travel allowances, firewood and tax relief, for instance, have been used in the Region. Some charity funds disbursed by imams have also encouraged a more results-based approach towards efficient TB prevention and care.

Migrant workers

Many patients are compelled to look for work, and many migrate to the Russian Federation to earn some income as they start to feel better, even before completing treatment. This is an important issue that needs to be raised during the upcoming global ministerial conference in Moscow.

Panel discussion: how TB-REP can improve government acceptance for policy-change

Key points from the interactions by participants were as follows.

Linking with TB-REP focal points

TB- REP focal points and project coordinators are perceived to have authority and exert a strong influence, especially in countries with Soviet-style vertical systems. Governments are showing strong commitment by designating influential vice-ministers as focal points, but not all countries have a nominated focal point. Many members had positive experiences with their national focal points, but a few have not yet managed to make contact. WHO country offices and network links with NTP managers have facilitated first contact with focal points.

Using international organizations as leverage

Participating at partner forums and meetings with international agencies such as UNAIDS and Médecins Sans Frontières increases CSOs' influence and results in better cooperation and efficient implementation. TB-REP grantees need to be actively involved and take advantage of the extra leverage that comes from connecting with international partners.

Reporting positive results

The extension of the TB-REP project beyond the end of the grant in 2019 depends on delivering concrete results that are significant from the donor's point of view. Competition for funding is very strong, and regional proposals for drugs and new diagnostic tools are more popular with funding agencies.

Being proactive

TB-REP members should take a proactive approach to connecting with their focal points and other policy leaders and include WHO, NTP managers, mayors, ministry officials and even members of parliament. TB-REP has the full support of the Global Fund and WHO, and must ensure that representatives are invited to policy and high-level meetings.

The overall objective of TB-REP is to reduce the admission rate and duration of stay in hospitals, but it also has responsibility for representing patients and communities. Consequently, TB-REP members must be well prepared, present targeted and clear arguments, and offer rational solutions.

WHO

WHO country offices and the Regional Office have a strong supportive role, and lines of communication to CSO representatives are always open. TB-REP missions in countries have included TB-REP focal points and working groups, but it is not always possible to announce schedules for monitoring visits well in advance.

Some positions in WHO country offices have now been integrated into joint TB/HIV/hepatitis positions as part of ongoing reforms. The WHO Barcelona course on health-systems strengthening for improved TB prevention and care will be available to TB-REP grantees.

Seeking support from elected officials

The influential role of elected officials is well recognized, but depends on members being able to cultivate a strong personal relationship with officials who may not remain in post for long durations. Some positive experiences were reported, but some participants found engaging local members of parliament difficult: they often do not understand why they need to be involved, or see no gains for their political future. Officials also may fail to be re-elected or lose their public influence due to internal political shifts.

Religious leaders

Mention of religious leaders promoted lively debate.

Religious leaders may have a strong influence on local government authorities and have been represented in country coordinating mechanisms. They may have a positive role if they are well informed, but some religious leaders and faith healers in rural areas can have a negative influence: this fact cannot be ignored. Religious leaders should not replace professional medical care and patient-support services. Increased awareness among religious leaders has resulted in preventive measures being taken at places of worship.

Reality on the ground

Advocacy in TB remains less popular than in HIV and harm-reduction programmes. Communication and advocacy tools are either lacking or too complex to be relevant to patients (some members shared examples of work in progress). Primary health-care workers, especially in rural areas, tend to be older and appear to resist change. Discrimination of patients and ex-patients by colleagues at work is common and long hospitalization renders many unemployed.

Cross-linkages between TB-REP components

Dr Viorel Soltan, Director, Centre for Health Policies and Studies

The primary goals of TB-REP are to decrease the burden of TB and DR-TB in the 11 recipient countries and promote the shift to people-centred care through advocacy, capacity-building and technical support. A blueprint of optimal models for TB service-delivery is being developed, led by the Centre for Health Policies and Studies in collaboration with WHO, the Global Fund, the London School of Hygiene and Tropical Medicine, the London School of Economics and Political Sciences, and the TB Europe Coalition. It looks at new approaches to health financing, human resources, access to services and financial protection and maps all components of TB services, taking into consideration basic and practical elements. It even defines commonly used terms, such as “primary health care” and “hospital admission and discharge”, to standardize country reporting. Several operational tools are also being developed, including a hospital-bed estimator based on epidemiological and policy trends.

Dr Soltan reminded participants that while qualitative and quantitative outcomes are listed in the TB-REP Theory of Change framework, those set by the Global Fund for reduction of hospitalization rates and duration of hospital stay are non-negotiable. These targets can be reached by informing and educating patients, creating a demand for people-centred ambulatory care and shifting health financing away from TB hospitals and sanatoria. Measurable outcomes from TB-REP may not be easy to quantify, but tangible products such as country roadmaps and practical operational documents are good examples.

The presentation was followed by a lively debate on how CSOs can support implementation of people-centred care.

Protecting patients

People-centred models of care need to put the needs of patients before those of health-care providers. Health systems have the power in some instances to curtail basic rights, such as parental rights to mothers who are hospitalized involuntarily. Such enforcement is known to discourage people from seeking early medical attention when symptomatic.

Overcome fear of TB

Fear of transmission is a strong driver for isolation of patients, especially among professional health-care workers, despite clear scientific evidence proving that patients become non-infectious within days of starting treatment. Nosocomial reinfection has been documented, especially in poorly managed infection control systems in hospital settings. TB doctors often resist change and many countries have much greater numbers of TB doctors (per patient) than licenced HIV specialists.

Advocating for flexible systems

Health-system financing in the Region is in a state of flux. Some countries compensate professional health-care workers and hospitals based on the number of TB beds, while others are moving towards social health insurance or more specific so-called bundled payments per TB patient. There is a danger that savings made from the reduction of TB hospital beds may not be earmarked for primary health-care services. Dealing with overcapacity of TB beds should not result in abolition of all hospital services for TB patients. CSOs must be aware of these traps.

This contrasts with health services for HIV/AIDS, which appear to be more supportive and more flexible.

Leading grassroots advocacy

The Centre for Health Policies and Studies (as the grant holder) works with country working groups and focal points, WHO and other technical partners to lead advocacy at the top levels of government. National working groups are responsible for designing roadmaps and countries have reached different levels of completion. TB-REP CSOs need to lead grassroots advocacy work and put pressure on policy-makers for quality care.

Looking beyond 2019

Continued financial support of newly established CSOs is a shared concern. The Global Fund appears to be gradually moving out of the Region and has strict rules on covering salaries. It is highly possible that new funding opportunities can be found if CSOs bring added value to programmes and communities. Building effective partnerships and sharing resources with other players may be a solution.

Breakout groups: the way forward, focusing on tangible and feasible outputs

Human resources and policy change

CSOs are aware of the health-resource challenges in different countries and can contribute by:

- investigating human-resource issues by performing needs assessments and reporting local human-resource problems by talking to patients and health-care workers in health centres;
- encouraging younger health-care workers to apply for positions in TB services and lobby governments to make these positions more attractive; and
- pushing for methods such as social services regulation and social contracting to compensate primary health-care staff and CSOs as they continue to provide social support to patients and their families.

Quality people-centred care

CSOs must ensure the shift to people-centred care maintains quality standards by:

- actively engaging with health-care workers, especially at local levels, and involve other groups (such as social workers);
- advocate to ensure that savings made from reducing hospital costs are retained in the TB budget (this may entail removing regulatory barriers and changing legislation);
- incentivising health-care workers and rewarding good outcomes;
- overcoming stigma and increasing awareness of TB in the community and among health-care workers by disseminating information and educating, while avoiding language that labels patients (such as “open cases”); and
- ensuring that CSOs can operate and grow by assuring financial and other support.

Increasing acceptance by governments

Concrete steps and actions by CSOs that can affect implementation of people-centred care include:

- evaluating and assessing legislation and policies on primary health-care services, as these differ across the Region, and identifying the potential contributions of CSOs;
- using the blueprint as a platform for initiating national dialogue between providers and patients;
- stimulating ongoing dialogue with national working groups, health-care workers and patients;
- reporting on and highlighting positive results of CSO activities in countries and the Region;
- adapting services according to patient needs and country contexts;
- evaluating performance and motivating health-care providers by celebrating good results, but also ensuring officials are held accountable; and
- tailoring evidence-based advocacy messages to specific target audiences.

Concluding remarks

- CSOs must ensure the needs of patients are understood and provided for as TB services shift to the primary health-care sector. Services must go beyond delivering drugs and provide a caring and supportive environment. This is the whole concept of people-centred care.
- TB programmes in countries have different needs and challenges. CSOs can respond by advocating for, and defining, a holistic package of care, bringing in new ideas and embracing new technology.
- CSOs in the Region are gaining confidence and experience and must look beyond TB-REP, while also focusing on delivering the pre-set targets. Financial sustainability is a key concern.
- All support should be given by WHO, the Global Fund and other partners to increase advocacy capacity in countries, helping CSOs to acquire new skills and proficiencies. The agreement of the Global Fund to finance CSO representatives to attend the WHO health financing course in Barcelona is a positive step.
- TB is high on regional and global agendas, as demonstrated by the upcoming Moscow global ministerial conference in 2017, the United Nations high-level meeting on TB in 2018, and the significant TB component in the WHO Regional Committee for Europe in 2018. This is a unique time for CSOs in the Region to contribute to the successful control of TB.

Annex 1

PROGRAMME

Day 1, Tuesday 7 March

Time	Topic	Speaker/lead
09:00–09:30	Session I Opening panel – “Setting the scene”, moderated by Dr Masoud Dara, WHO Regional Office for Europe	Dr Nedret Emiroglu , WHO Regional Office for Europe Dr Hans Kluge , WHO Regional Office for Europe Dr Lucica Ditiu , Stop TB Partnership (STP) Dr Viorel Soltan , Centre for Health Policies and Studies (PAS) Dr Uldis Mitenbergs , the Global Fund to fight Aids, TB and Malaria (Global Fund) Ms Fanny Voitzwinkler , TB Europe Coalition (TBEC) Mr Safarali Naimov , former MDR-TB patient
09:30–09:50	13 years to ending TB – can we be there and how?	Dr Lucica Ditiu , STP
09:50–10:10	Discussion	Chair session I; all participants
10:10–10:30	Session II Update on TB-REP project implementation	Dr Stela Bivol , PAS Ms Yuliya Chorna , ICF “Alliance for Public Health”
10:30–10:45	Discussion	Chair session II; all participants
11:15–12:00	Session III Panel discussion with questions and answers: update on TB-REP blueprint development and guiding principles of people-centred TB models of care, moderated by Dr Martin van den Boom, WHO Regional Office for Europe	Ms Yuliya Chorna , ICF “Alliance for Public Health” Mr Timur Abdullaev , ex-patient and civil society organization (CSO) representative Dr Ihor Perehinets , WHO Regional Office for Europe Ms Regina Winter , WHO Regional Office for Europe Mr Paul Sommerfeld , TB Alert Mr Safarali Naimov , former MDR-TB patient

Time	Topic	Speaker/lead
		Ms Oxana Rucsineanu , Moldova National Association of TB Patients
12:00–12:30	Session IV Presentation of regional TB-REP advocacy strategy and strategic directions	Ms Yuliya Chorna , ICF “Alliance for Public Health” Ms Fanny Voitzwinkler , TBEC
12:30–13:00	Discussion	Chair session IV; all participants
14:00–14:30	Session V Updates from partners on regional proposals and TB-REP relevant initiatives other than TB-REP (10 minutes each): <ul style="list-style-type: none"> • ECUO¹ regional project • Stop TB Partnership • Global and Regional TB Caucus initiative 	Mr Vladimir Zhovryak , ECUO Mr Gregory Paton , STP Mr Matthew Oliver , Global TB Caucus
14:30–15:30	Panel discussion: linkages and synergies between TB-REP and other regional work	Chair session V; all presenters of session V; representatives of the WHO Regional Office for Europe
16:00–17:00	Session VI Panel discussion on first set of country advocacy strategies with a focus on lessons learnt and challenges tackled, particularly with regards to contributing to improving people-centred care from community and primary health care perspectives	Chair session VI; TB-REP civil society organization (CSO) representatives of Azerbaijan, Belarus and Georgia; representatives of PAS, STP, WHO, TBEC, ICF “Alliance for Public Health”
17:00–17:15	Key messages and wrap-up Day I	Mr Timur Abdullaev , ex-patient and CSO representative

¹ ECUO = East Europe and Central Asia Union of People Living with HIV.

Day 2, Wednesday 8 March

Time	Topic	Speaker/lead
09:00–09:15	Summary of Day 1, outline for Day 2	Dr Martin van den Boom , WHO Regional Office for Europe, and Mr Gregory Paton , STP
09:15–10:30	Session VII Panel discussion on the second set of country advocacy strategies with focus how TB-REP CSOs can contribute to addressing the challenge of changing human resources situation, within the process of rendering TB care more people-centred.	Chair session VII; TB-REP CSO representatives of Armenia, Kazakhstan and Tajikistan; representatives of PAS, STP, WHO, TBEC, ICF “Alliance for Public Health”

Time	Topic	Speaker/lead
11:30–12:45	Session VIII Panel discussion on how TB-REP CSOs can improve the acceptance by governments for TB-REP favourable policy-change	Chair session VIII; TB-REP CSO representatives of Kyrgyzstan, the Republic of Moldova and Ukraine; Representatives of PAS, STP, WHO, TBEC, ICF “Alliance for Public Health”, TB Caucus.
14:00–14:20	Session IX Presentation of possible cross-linkages between different TB-REP components with a focus on how CSOs could further contribute	Dr Stela Bivol , PAS
14:20–14:40	Discussion, question and answers	All participants, Dr Stela Bivol , PAS and Dr Martin van den Boom , WHO Regional Office for Europe
14:40–15:30	Session IX (contd) Way forward: groupwork in breakout groups focusing on tangible and feasible outputs	All participants, guided by facilitators
16:00–16:30	Presentations from break-out groups (up to 10 minutes per group)	Chair session IX; all participants
16:30–17:00	Session X Wrap-up and next steps	Dr Lucica Ditiu , STP Dr Hans Kluge , WHO Regional Office for Europe Dr Viorel Soltan , PAS Ms Fanny Voitzwinkler , TBEC Mr Timur Abdullaev , ex-patient and CSO representative
17:00–17:15	Closing	Dr Uldis Mitenbergs , Global Fund Dr Viorel Soltan , PAS Dr Masoud Dara , WHO Regional Office for Europe

Annex 2

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